

# **DDDS Nurse Consultant Resource Guide**



**DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES  
NURSE CONSULTANT RESOURCE GUIDE  
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## **FORWARD**

This Nurse Consultant Resource Guide is intended to be a teaching/learning tool for Nurses working with and for the Division of Developmental Disabilities Services. Each section includes at the end a place where the Nurse can verify and the supervisor can confirm that the information has been read by the Nurse and all questions have been answered by the supervisor or others. It is also intended to serve as a reference for Nurses even after they have completed their Orientation.

## WELCOME TO CONSULTATIVE NURSING SERVICES

### WITH DDDS

## ***Being a Nurse Supporting People with Developmental Disabilities is a one-of-a-kind job!***



Each person receiving services from the Division of Developmental Disabilities Services (DDDS) has a team of professionals that provide support. As a Nurse you will be a member of that support team, but you will also play many different roles in the lives of the people you support. Health promotion and advocacy, teaching people with developmental disabilities and those who support them about health conditions and treatments and overseeing a person's general health care are all duties you will perform as a Nurse working with DDDS.

You will discover that there are some incomparable duties and issues not common to other Nursing positions. As you provide support to people who have developmental disabilities (DD) or intellectual disabilities (ID), it is important to remember that some issues and concerns are unique to those you will be working with and others, while not unique, may affect the people you work with at different ages or in different ways than those in the general population. This manual is designed to provide an overview of the typical consultative services a Nurse will provide.

This introductory section will provide information about some common health care issues that challenge those you will be working with. For example, some people may do things that upon first observation seem to be a behavioral issue. However, it is often the case that there is an underlying health problem causing the behaviors and resolution of the health problem can very often resolve issues around behavior as well. *Whenever someone begins to exhibit behaviors that have not been evident before, or when there is a sudden increase in challenging behaviors, issues of health should be the first thing considered.* It is sometimes the case that people with developmental disabilities are not able to use spoken words, or to articulate, what is wrong or where it hurts. Therefore, the support team, and in particular the Nurse, must look first at possible underlying health issues. Issues related to health should be ruled out and/or treatment delivered, in conjunction with any type of behavior support plan, especially those that are restrictive in nature.

## ***“Diagnostic Overshadowing”***



Diagnostic overshadowing occurs when the presence of one diagnosis interferes with the detection of other diagnoses. Diagnostic overshadowing can seriously affect the people you support, health professionals and the health-care system. Malignant or rapidly evolving conditions can cause great harm if undiagnosed and Healthcare Professionals may have to endure lawsuits and loss of trust.

People living with developmental disabilities have sometimes been deprived of needed treatment and even compassion because their illness has been seen through the lens of their disability. It is often a tendency of medical professionals to attribute signs and symptoms of other illnesses to a person’s developmental disability, when in fact there are other causes. Because many in the healthcare profession do not understand developmental disability, they may not understand that illness can manifest in different ways for people who have developmental disabilities. *People with disabilities often show symptoms in a way that is different from the “typical” symptoms seen in the general population.*

In fact, for many years it was thought that people with developmental disabilities could not possibly have mental illness, perhaps could not even have the same feelings, as the typical population. This “diagnostic overshadowing” — the tendency to let the developmental disability diagnosis block recognition of other illness — still lingers. When a person with a developmental disability acts in uncharacteristic or even dangerous ways, it is still all too often viewed as “misbehavior”, not as a possible symptom of an undiagnosed medical or mental illness.

As a Nurse working to support people with developmental disabilities, it will be necessary for you to remind others in the healthcare profession that there are only certain and very specific signs and symptoms associated with a developmental disability. *Anything that is not specifically a result of a person’s developmental disability should be thoroughly examined.*

## **Health Care Basics for People Who Have Developmental Disabilities**

### **The “FATAL FOUR”**

People with disabilities of all kinds have unique concerns when it comes to their health. Healthcare Professionals must be aware of “The Fatal Four” in order to provide comprehensive supports to people living with disabilities. The “Fatal Four” include aspiration, constipation, dehydration and seizures.





## Aspiration

Aspiration is a common problem among people who have difficulty swallowing or “dysphagia”. Aspiration means that food or fluids that should go into the stomach go into the lungs instead. When material goes into the lungs it can cause Aspiration Pneumonia. Aspiration Pneumonia can worsen quickly if not properly identified and treated. Aspiration Pneumonia can result in death. The Nurse must become familiar with the signs and symptoms of aspiration and aspiration pneumonia.

### Common signs of dysphasia and/or aspiration are:

- Coughing before or after swallowing
- Excessive drooling, especially during meals
- Pocketing food inside the cheek
- Choking on certain foods, for example bread
- Nose running or sneezing while eating
- Trouble chewing
- Trouble swallowing certain types of food or liquids
- Taking a very long time to finish a meal
- Getting tired while eating
- Refusal to eat certain foods or finish a meal
- Complaining of something caught in the throat
- A gurgling voice during or after eating or drinking
- Excessive throat clearing after eating
- Repeated episodes of choking, frequent colds, pneumonias or “allergies”
- Unexplained weight loss
- Unexplained fevers that come and go
- Coughing when lying flat or sitting up quickly from a reclined position

It may take some time for symptoms of **aspiration pneumonia** to become apparent. Aspiration pneumonia can quickly get worse if it is not properly diagnosed and treated. *Aspiration pneumonia can be life-threatening and should be considered an emergency.*

### Common signs and symptoms of aspiration pneumonia:

- Frequent cough - foul-smelling mucus or phlegm - may contain pus or streaks of blood.
- Sputum greenish in color and the person may cough up frothy fluid.
- Shortness of breath/noisy breathing.
- Heartbeat or breathing may seem faster than normal.
- Fever or chills accompanied by sweating.
- Pain in the chest while coughing or when taking a deep breath.
- Trouble swallowing
- Feeling as if something is stuck in their throat.
- Confusion, dizziness, faintness, unusually upset or anxious.

Keep a close watch for any symptom of aspiration or aspiration pneumonia and educate direct support staff about what to watch for and what to do if they see the signs. If necessary, implement a formal plan of monitoring and reporting until the condition has resolved.

## **Constipation**

The normal length of time between bowel movements varies widely from person to person. Some people have bowel movements three times a day; others, only one or two times a week. However, going longer than three days without a bowel movement is too long. After three days, the stool or feces become hard and more difficult to pass.

### **Common causes of constipation include:**

- Inadequate fluid intake.
- Inadequate fiber in the diet.
- A disruption of regular diet or routine (for example, while traveling).
- Inactivity or immobility.
- Eating large amounts of dairy products.
- Stress.
- Resisting having bowel movements (sometimes results from pain due to hemorrhoids).
- Overuse of laxatives (stool softeners) which can weaken bowel muscles.
- Hypothyroidism.
- Neurological conditions such as Parkinson's disease or multiple sclerosis.
- Antacid medicines containing calcium or aluminum.
- Medicines (especially narcotics, antidepressants, or iron pills).
- Depression.
- Eating disorders.
- Irritable bowel syndrome.
- Pregnancy.
- Colon cancer.

### **Symptoms of constipation may include:**

- Fewer bowel movements than usual
- Postures that indicate the person is withholding stool (standing on tiptoes and then rocking back on the heels of the feet, clenching buttocks muscles, other unusual “dancelike” behaviors. Such postures can sometimes be mistaken as attempts to “push”)
- Abdominal pain and cramping
- Painful or difficult bowel movements
- Hard, dry, or large stool
- Stool in the person’s underwear

# 2009HEALTH ALERT

## BOWEL OBSTRUCTION ALERT!!!!!!

<p><b>Signs and Symptoms of Small Bowel Obstruction</b></p> <ul style="list-style-type: none"> <li>• <b>Abdominal pain</b> (waves of cramping pain around the naval; rapid breathing and rapid pulse during cramping)</li> <li>• <b>Bloating</b> (gurgling sounds may be heard from the stomach)</li> <li>• <b>Vomiting</b> (vomit can be green if the obstruction is in the upper small intestine or brown if the obstruction is in the lower small intestine)</li> <li>• <b>Elimination Problems</b> (constipation and the inability to pass gas or diarrhea and some passing of gas)</li> </ul>	<p><b>What is considered normal bowel function?</b> Normal frequency of bowel movements can range from 3 times a day to 3 times a week. A person's pattern of bowel movement is considered normal if it does not represent a change in the usual frequency or character of the stool and if passing stool is not associated with straining or pain.</p> <p><b>What is constipation?</b> Constipation is bowel movements that occur less than 3 times a week (less than every other day or every third day) OR stools that are small, hard and difficult to pass.</p> <p><b>What cause constipation?</b> Constipation can be caused by poor or irregular bowel habits, not drinking enough fluids, eating a diet low in fiber, physical inactivity, intestine or rectal surgery, many prescription and non-prescription medications, medical conditions such as stroke, cancer or hemorrhoids and increased emotional or physical stress.</p> <p><b>What is bowel obstruction?</b> A bowel obstruction is a partial or complete blockage in the intestines that prevents gas, fluids, or solids from moving through the intestines normally. Blockage can occur in the small intestine (a small bowel obstruction) or in the large intestine (a large bowel obstruction). In very severe cases the blood supply to the bowel can be cut off (bowel strangulation). This requires <b>immediate emergency medical treatment</b>.</p> <p>A bowel obstruction can be fatal if not recognized and treated in time.</p> <p><b>What causes a bowel obstruction?</b> A bowel obstruction can be caused by adhesions (bands of scar tissue from previous surgeries), tumors (growths) that block the bowel, bowel stricture (changes in the shape of the bowel), certain diseases, and certain medications.</p> <p><b>How can constipation be prevented?</b></p> <ul style="list-style-type: none"> <li>• <b>Develop regular bowel habits</b> (schedule toileting after meals, allow 15 minutes of undisturbed time on the toilet and do not ignore the urge to have a bowel movement as this can lead to constipation)</li> <li>• <b>Eat a well-balanced, fiber rich diet on a regular schedule</b></li> <li>• <b>Drink enough non-caffeinated, non-alcoholic fluids</b> (6-8, 8 ounce glasses per day)</li> <li>• <b>Exercise</b>, such as walking, running, swimming or other passive exercises for those who have limited mobility or are restricted to bed rest</li> <li>• <b>Take all laxatives, stool softeners, lubricants and/or enemas that are prescribed by the physician</b> (drinking enough fluids is very important when taking bulk laxatives [fiber supplement] and stool softeners)</li> </ul>
<p><b>Large Bowel Obstruction</b></p> <ul style="list-style-type: none"> <li>• <b>Abdominal pain</b> (usually pain below the naval; can be either vague or mild or sharp and severe)</li> <li>• <b>Bloating</b> (usually occurs around the naval and in the pelvic area)</li> <li>• <b>Vomiting</b> (this is not common, it usually occurs late in the illness)</li> <li>• <b>Constipation or Diarrhea</b> (either may occur depending on how complete the obstruction is)</li> </ul>	
<p><b>The symptoms of constipation and bowel obstruction can look like the "flu".</b></p>	

**REMEMBER:**

- **Symptoms of constipation that last longer than 2 weeks, symptoms of constipation that are severe (regardless of duration), changes in normal bowel habits and complications of constipation should be evaluated by a physician.**
- **Bowel Obstruction is ALWAYS fatal if not recognized and treated within 36 to 48 hours. (In addition, other fatal complications can develop from bowel obstruction such as sepsis, which is an infection throughout the body.)**
- **It is possible to have diarrhea (loose stools) and still have constipation or a bowel obstruction.**
- **Closely monitor an individual's bowel function if he/she has had recent abdominal surgery, injuries, medication changes, diet changes or changes in activity level.**

## Dehydration

People with disabilities, in particular older adults, have an increased chance of becoming dehydrated because they:

- Don't drink enough because they do not feel as thirsty as other people.
- Have kidneys that do not work well.
- Choose not to drink because of an inability to control the bladder (incontinence).
- Have stomach and bowel disorders that cause fluid to move through the body too quickly.
- Have a physical condition which makes it:
  - Hard to drink or hold a glass.
  - Difficult or painful to get up from a chair.
  - Painful or exhausting to go to the bathroom.
  - Hard to talk or communicate to someone about symptoms.
  - Necessary to take medication that increases urine output.

***Anytime someone you support has an illness that causes high fever, vomiting, or diarrhea, you should instruct direct support staff to watch closely and report to you ANY symptoms of dehydration.***

**Symptoms of mild to moderate dehydration include:**

- Dry, sticky mouth
- Sleepiness or tiredness
- Thirst
- Decreased urine output (eight hours or more without urination)
- Few or no tears when crying
- Dry skin
- Headache
- Constipation
- Dizziness or lightheadedness

**Symptoms of severe dehydration (a medical emergency):**

- Extreme thirst
- Irritability and confusion
- Very dry mouth, skin and mucous membranes
- Lack of sweating
- Little or no urination — urine that is produced is dark yellow or amber
- Sunken eyes
- Dry skin that lacks elasticity and doesn't "bounce back" when pinched into a fold
- In infants, sunken fontanel (the soft spots on the top of a baby's head)

- Low blood pressure
- Rapid heartbeat
- Rapid breathing
- No tears when crying
- Fever
- In serious cases, delirium or unconsciousness

### **Seizure Disorder (Epilepsy)**

Seizures of all types are caused by disorganized and sudden electrical activity in the brain.

About 2 in 100 people in the United States will experience an unprovoked seizure once in life. A solitary seizure doesn't mean someone has a seizure disorder (epilepsy). At least two unprovoked seizures are generally required for diagnosis of a seizure disorder.

Causes of seizures can include:

- Abnormal levels of sodium or glucose in the blood
- Brain infection, including meningitis
- Brain injury
- Brain problems that occur before birth (congenital)
- Brain tumor (rare)
- Choking
- Drug abuse
- Epilepsy
- Fever
- Head injury
- Heart disease
- Heat illness (heat intolerance / heat exhaustion / heat stroke)
- High fever
- Illicit drugs, such as angel dust (PCP), cocaine, amphetamines
- Kidney or liver failure
- Low blood sugar
- Poisoning
- Stroke
- Toxemia of pregnancy
- Uremia related to kidney failure
- Very high blood pressure (malignant hypertension)
- Venomous bites and stings
- Withdrawal from alcohol after drinking a lot frequently
- Withdrawal from certain drugs, including some painkillers and sleeping pills
- Withdrawal from benzodiazepines (such as Valium)

It may be difficult to tell if someone is having a seizure, especially if you are not yet familiar with the person and his or her typical way of being. Some seizures may only cause a person to have staring spells and may go unnoticed. Specific symptoms depend on what part of the brain is involved and they can occur suddenly.

**Symptoms of Seizure may include:**

- Brief blackout followed by period of confusion (can't remember a period of time)
- Changes in typical behavior such as picking at one's clothing
- Drooling or frothing at the mouth
- Eye movements
- Grunting and snorting
- Loss of bladder or bowel control
- Mood changes such as sudden anger, unexplainable fear, panic, joy, or laughter
- Shaking of the entire body
- Sudden falling
- Tasting a bitter or metallic flavor
- Teeth clenching
- Temporary halt in breathing
- Uncontrollable muscle spasms with twitching and jerking limbs

Symptoms may stop after a few seconds or minutes, or continue for 15 minutes. They rarely continue longer.

A person may have warning symptoms, sometimes called an “aura”, before seizures, such as:

- Fear or anxiety
- Nausea
- Vertigo
- Visual symptoms (such as flashing bright lights, spots, or wavy lines before the eyes)

All direct support staff who work with a person who has a seizure disorder are required to receive specific training related to the person's seizures and the proper care and reporting of events. However, you should advise/remind direct support professionals to call 911 (or the local emergency number) if:

- This is the first time the person has had a seizure.
- A seizure lasts more than 5 minutes or as otherwise directed.
- The person does not awaken or return to typical behavior after a seizure.
- Another seizure starts soon after a seizure ends.
- The person had a seizure in water.
- The person is pregnant, injured, or has diabetes.
- There is anything different about a seizure compared to the person's usual seizures.
- As outlined in the person's Diastat protocol (as applicable).

## Developmental Disability and Co-Morbidity

Some disabilities are more frequently associated with co-morbid conditions (i.e., cerebral palsy with vision impairment). Clinicians must be aware of the likelihood of these co-morbidities, and recognize that cognitive and communication difficulties can present barriers to accessing health care. When a person has significant communication difficulties, whether due to cognitive, social or physical limitations, additional communication skills and strategies will be required of the Nurse to ensure good communication with the person, and where appropriate, family members and/or Direct Support Professionals.

Clinicians should not let the developmental disability distract from or overshadow other health problems.

Many of the people you work to support will have multiple diagnoses and multiple disabilities. Still others will acquire disabilities in later life, including sensory, psychiatric, musculoskeletal and neurological disabilities. These can have a significant impact on the person and need to be addressed within the context of the person's life.

It's important for a Nurse working with DDDS to have an understanding of the different types of disabilities, conditions which co-exist, and those that occur earlier or at an increased rate in people who have developmental disabilities.

Different diagnoses and the estimated rate at which they occur in people with Developmental and Intellectual Disabilities:

Co-morbid Conditions	Estimated Rate of Occurrence in People with Developmental/Intellectual Disability (DD/ID)
Autism Spectrum Disorders	75%
Attention Deficit Hyperactivity Disorder	4 to 11%
Disorders of the brain due to General Medical Conditions	Seizure Disorder – 15 to 30%, Motor impairments – 20 to 30%, Sensory Impairments – 10 to 20%
Schizophrenia	Similar rates in persons with and without DD/ID
Mood Disorders, e.g., Depression	Under-diagnosed in persons with developmental/intellectual disability; estimated to occur at a rate equal to or greater than those without DD/ID
Anxiety Disorders	25% in outpatient samples
Posttraumatic Stress Disorder	Significantly under-diagnosed in people with developmental/intellectual disabilities
Obsessive-compulsive Disorders	Difficult to differentiate from self-injurious, self-stimulatory, or stereotypic behaviors associated with other disorders
Eating Disorders	Developmental/Intellectual disability is a predisposing factor for eating disorders such as Pica

## Disability Types

There are many types of disabilities, such as those that affect a person's:

- Hearing
- Vision
- Movement
- Thinking
- Remembering
- Learning
- Communicating
- Mental health
- Social relationships

Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see. When working with people who have disabilities, fundamental principles that guide good practice include clearly focusing on and respecting the person, an awareness of the impact the person's disability has on their life-style and the need to employ the same standards of care that apply to people without a disability.

People who have disabilities can and do have the full range of medical conditions that affect people without disabilities and they require access to appropriate services. This includes access to the full range of preventive health services such as smoking cessation, nutritional and other community based health initiatives.

### Understanding the Difference between Developmental Disability and Intellectual Disability

The term *developmental disability* refers to a severe and chronic disability that is attributable to a mental or physical impairment that begins before an individual reaches the age of 22. These disabilities include *intellectual disability*, cerebral palsy, epilepsy, autism, and closely related conditions that require similar treatment. Developmental disabilities result in substantial limitations in three or more areas of major life activities:

- capacity for independent living
- economic self-sufficiency
- learning
- mobility
- receptive and expressive language
- self-care
- self-direction

Intellectual Disability is one type of Developmental Disability. The term "*intellectual disability*" is a relatively new term. On April 25, 2003, as part of the annual celebration of the Americans with Disabilities Act, President George W. Bush renamed the President's Committee on Mental



Retardation to the President’s Committee for People with Intellectual Disabilities. The President’s Committee for People with Intellectual Disabilities sought to eliminate the two words that create problems for people with “mental retardation.” The word “mental” has often caused confusion with the term “mental illness” and the word “retardation” has often led to the use of offensive name-calling.

*Intellectual disability* is a below-average cognitive ability with three (3) characteristics:

- Intelligent quotient (or I.Q.) is between 70-75 or below
- Significant limitations in adaptive functioning (the ability to adapt or complete everyday life activities such as self-care, socializing, communicating, etc.)
- The onset of the disability occurs before age 18.

Intelligence refers to general mental capability and involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Studies show that somewhere between one (1) percent and three (3) percent of Americans have intellectual disabilities. The many causes of intellectual disabilities include physical, genetic and/or social factors.

The most common syndromes associated with *intellectual disabilities* are autism spectrum disorders (ASD), Down syndrome, Fragile X syndrome and Fetal Alcohol Spectrum Disorder (FASD). Genetic conditions (Down syndrome and Fragile X syndrome), problems during pregnancy (mother consuming alcohol while pregnant), complications at the time of birth, health problems such as whooping cough, measles or meningitis and exposure to environmental toxins like lead or mercury can all cause *intellectual disabilities*.

### **Down Syndrome and Alzheimer’s Dementia**

People with Down Syndrome are more likely than the general population to develop Alzheimer's dementia and at an earlier age. This table shows the percentage of people with Down Syndrome who develop dementia at different ages:

<b>Age</b>	<b>Percentage with clinical signs of dementia.</b>
30's	2%
40's	10-15%
50's	33%
60's	50-70%

Dementia is characterized by the progressive deterioration of mental abilities, behavioral changes and a decline in skills. Symptoms of dementia can be subtle and develop slowly, and are often wrongly attributed to the disability. Early signs may not be apparent because care-givers will often “compensate” for the person by guiding and prompting them, or by filling gaps in their speech.

## **Some early symptoms that may occur in people with Down Syndrome & Alzheimer's Dementia**

- Forgetfulness (loss of short-term memory, but intact long-term memory)
- Confusion (e.g., putting clothes on the wrong way)
- Slowing down (e.g., in walking / eating / speaking)
- Speech & language changes (e.g., repetitive questioning)
- Changes in sleep (e.g., night-time wandering)
- Loss of skills (e.g., using stereo / phone)
- Problems socializing (e.g., becoming more reclusive)
- Increased obsessions (doing things over & over again)
- Altered personality (e.g., less outgoing)
- Problems with balance (e.g., unsteady walking)
- Emotional difficulties (e.g., unexplained crying / screaming)
- Visual hallucinations
- Unexplained body aches & pains

## **Developmental Disability and Depression**

- One person out of five suffers from depression at some point in their lives. People with developmental disabilities suffer from depression at least as often as people without developmental disabilities.
- Depression decreases a person's ability to enjoy life.
- Depression can lead to poor health.
- It can be hard to recognize signs of depression in someone with developmental disabilities, especially if they do not communicate well.
- There may be people with developmental disabilities who need help for depression, but do not get help because they are unable to communicate how they feel.

There are different types of depression:

**Major depression** interferes with everyday life. This kind of depression can change how people sleep, eat, and feel about themselves. Major depression can also make it hard for a person to concentrate, work, socialize, or enjoy life events. A person may suffer from major depression once, get better, and never become depressed again. But many people feel depressed on and off for their whole lives. Without help, major depression can lead to heart disease, alcohol or drug abuse, and suicide.

**Dysthymia** is less severe than major depression, but Dysthymia can still keep a person from feeling well and meeting the challenges of everyday life. Dysthymia also tends to last longer than major depression.

**Bipolar Disorder** (manic-depressive illness) often makes a person change very rapidly, from feeling depressed and doing very little, to feeling very happy and having a very high level of activity (mania). Bipolar disorder affects how people act and think and can lead people to make bad decisions.

**Seasonal Affective Disorder (SAD)** causes a person to feel very sad during times of the year when there is less natural sunlight—in the winter, for example. People with Seasonal Affective Disorder normally feel better in the spring and summer.

### **How can you tell when someone you support has depression?**

The people you support may not be able to talk about their moods or explain that they feel sad. It is important for you to pay attention to any changes in a person's behavior. If a person does not communicate well, to know that they feel depressed, you must observe what they do. The following table lists some symptoms of depression you might observe in people who have developmental disabilities:

<b>Symptoms</b>	<b>What You Might Observe</b>
Depressed (sad) mood	Cries or moans for long periods of time Seems to cry without reason Smiles or laughs less than usual Has a sad facial expression Whines and complains often
Acting out more often than usual	Has an angry expression Yells, screams, or swears Spits at others Tries to injure self
Acting tired / not having any energy	Spends more time sitting or lying down Has trouble getting out of bed in the morning
Sleeping more or less than normal	Sleeps more than 11 hours a night Takes long naps or naps frequently Wakes up earlier than usual Has trouble falling asleep Wakes up in the middle of the night

Symptoms	What You Might Observe
Changes in weight or appetite	Refuses to eat or eats more than usual Sudden increase or decrease in weight Steals food Is disruptive at meal times
Losing interest in activities	Doesn't participate in favorite activities Doesn't seem to enjoy activities Spends more time alone than usual Refuses most work or social activities
Acting worried, troubled or very slow to respond	Doesn't sit down Paces or walks rapidly Stops talking or talks more slowly than usual Moves very slowly
Talking about death or suicide	Talks about people who have died Threatens to kill self Shows a strong interest in violent movies or television shows
Feeling worthless	Statements like "I'm no good for anyone." Spends more time alone Pushes other people away
Finding it hard to think or concentrate	Can't focus on work or activities Is easily distracted Has memory loss Doesn't get as much done at work Has trouble taking care of self

**These are examples of some of the things that may lead to depression.**

Life Event	Examples
Loss	The death of a loved one Breaking up with someone or getting a divorce Losing a job Loss of a favorite staff member

Life Event	Examples
Stress	Being the victim of abuse Being the victim of a crime Having problems with friends or family Problems with money Problems at work or in school Drug or alcohol abuse
Loss of control due to physical or other limitations	Long term illness or injury Needing assistance from others Loss of independence Loss of self-confidence Feeling a lack of control over one's own life
Social limitations	Difficulty expressing oneself Finding it hard to get a job or earn money Having difficulty making friends Social isolation

### **If you believe a person you support is depressed ...**

Generally, a person should see their doctor if they experience symptoms of depression for longer than two weeks or if symptoms are serious enough to disrupt their daily routine. However, it can take a long time to notice symptoms of depression in people with developmental disabilities. Changes in behavior related to depression (for example, eating or sleeping less, forgetting to take medication, etc.) may have serious effects on a person's health. It's important for you to act quickly if you think a person you support is depressed.

- Encourage the person to talk to you. Help them to explain how they feel. Ask about what is happening in their life. Pay attention and be supportive. Take what they say seriously; be careful not to dismiss any of the feelings they describe. Be alert for any signs that they may be thinking of hurting themselves (for example, talking about death).
- If the person does not use speech to communicate, watch them more carefully and instruct direct support staff to do the same. Document symptoms or changes in behavior. Note when the changes first appeared. Report anything that has changed recently in the person's life.
- Make an appointment with the person's primary doctor. Some physical conditions and some medications can cause symptoms similar to depression. A doctor will be able to rule out physical or medical causes. He or she may recommend a visit to a psychiatrist or psychologist.

## **Post Traumatic Stress Disorder (PTSD)**

People who experience disabilities are more likely than people without disabilities to be abused physically, emotionally, or sexually. Ryan (1994) estimates that 61% of the people with developmental disabilities living in a hospital setting met the criteria for PTSD.

Traumatic reactions occur when action is not effective. When neither resistance nor escape is possible, the human system of self-defense becomes overwhelmed and disorganized. Each component of the ordinary response to danger tends to persist in an altered and exaggerated state after the actual danger is over. Traumatic events produce profound and lasting changes in physiological arousal, emotion, cognition and memory. Traumatic events may also sever these typically integrated functions from one another. The traumatized person may experience intense emotion without clear memory of the event, or may remember everything in detail but without emotion. They may find themselves in a constant state of irritability without knowing why. Traumatic symptoms have a tendency to become disconnected from their source and to take on a life of their own.

Traumatic events may include one or more of the following:

- Separation from primary relationships at an early age
- Frequent moves between residential placements
- Institutionalization
- Physical, verbal, emotional abuse or neglect
- Loss of parent, sibling, or significant other
- Significant medical problems/procedures
- Extended hospitalization / institutionalization

In the name of treatment, some professionals may expose individuals to trauma. Although not routinely approved or sanctioned for use by the DDDS or affiliated service providers, the following procedures are all too common in the personal history of people who experience disabilities:

- Time out / Isolation / Seclusion
- Physical or mechanical restraint
- Facial screening (covering the face)
- Ammonia or other aversive substances

**Symptoms of PTSD may include:**

- Unexplained episodes of anger or rage.
- Inexplicable episodes of screaming, throwing things or destruction of property.
- Reactions seeming out of proportion to the situation (people who have an out of proportion reaction to moderately stressful situation may have had something worse)

happen to them in the past that is stirred up by the event).

- Abrupt physical assault (often on people they like).
- Extreme fear of people they know and trust at times.
- Calling someone they know by a different name.
- Appearing unfocused, not “with it”.
- Sometimes behaving like they are somewhere else.
- Dissociative experiences (detachment from physical and emotional reality).

## Introduction

Section Name	Date Read/Completed	Initials
Welcome to Nursing with DDDS		
Diagnostic Overshadowing		
HealthCare Basics for People who Have Developmental Disabilities		
The “Fatal Four”		
Developmental Disability and Co-Morbidity		
Disability Types		
Understanding the Difference Between Developmental Disability and Intellectual Disability		
Down Syndrome and Alzheimer’s Dementia		
Intellectual/Developmental Disability & Depression		
Post Traumatic Stress Disorder (PTSD)		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse’s Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date



## **Section 1 – NURSING ASSESSMENTS**

### **The Electronic Comprehensive Health Assessment Tool (E-CHAT)**

The Electronic Comprehensive Health Assessment Tool (E-CHAT) is an in-depth health evaluation. This is an on-line tool that assesses a person's current symptoms and health history and calculates overall activity level. A summary is produced when the E-CHAT is completed. This summary includes recommendations from which a plan of care may be developed. This document is completed by the Nurse prior to admission and updated as necessary to reflect changes in the person's health condition. The E-CHAT must minimally be reviewed annually and submitted 2 weeks prior to the Essential Lifestyle Plan meeting date. The goal of this assessment is to proactively identify healthcare and medical needs and to assist the Nurse to adhere to Best Practice. It is the expectation that the Nurse will provide appropriate follow-up and recommendations to the team to help address any health concerns.

Until further development of documentation options are completed in the electronic record, the health supports will be attached in the "Attached Safeguards" section of the ELP by the nurse. The former "Significant Medical Condition" section of the ELP Nursing Assessment will be used to document each of the individual's conditions along with information that staff need to know in order to support the individual with his or her health care needs. To avoid anyone other than the nurse consultant making changes to this attachment, he/she will save the document in PDF format.

The Nurse Consultant will keep this document up to date as the individual's health status warrants in order for staff to always have the most current information available. Any revisions will be completed on the word document with the date the revision(s) was completed and attached to the original ELP. When the changes occur, the nurse will complete a T-log designating such as a high priority and also document the same in the comment section at the bottom of the ELP. This will ensure all staff are informed about the revised supports for the individual. The nurse shall email a PDF copy of the original/revised health supports to the individual's day program provider.

### **Fall Assessment**

An additional component of the on-line Health Assessment is the completion of a Fall Risk Assessment tool. The purpose of this screening is to identify persons who are at risk for falls, to protect them from injury and to promote safety. The Fall Assessment tool must be updated any time there are changes in status, but minimally at the same time the health assessment is completed/updated, which is upon admission and prior to the person's annual Essential Lifestyle Planning (ELP) meeting. The Nurse should review Health Care Service Protocol #3 Fall Management Guidelines for nursing responsibilities. This protocol can be located in the DDDS

public folder. For any person scoring a 6 or above, development of an individualized fall prevention plan is required.

### **Aspiration Assessment**

Aspiration is a major health issue that is more common in people who have a Developmental Disability than in the general population. It can lead to severe morbidity and even death. An Aspiration/Choking Risk assessment is completed with the goal of effectively identifying persons who are at risk and provides support staff with interventions to manage safe eating practices. Aspiration/Choking Protocol #6 is available for review of nursing responsibilities and can be located in the DDDS public folder. Nursing expectation includes the completion of an assessment at the time of admission, annually to coincide with updating the electronic nursing assessment, if there is a change in health status or if risks are identified. Requirements are outlined in the protocol for scores indicating a moderate or severe risk.

### **Medical Alert Form**

This form is completed for people considered to have the potential for life threatening or medically significant health issues. This document is completed upon admission, reviewed at the time of the annual assessment and updated as changes occur. This form is printed on bright green paper and filed in the front page of the MAR if living where one is used. In a shared living home, the form is filed in the front page of the Shared Living Provider (SLP) notebook. A copy must also be sent to the person's day service program. Please refer to Medical Alert Form Guidelines for additional information.

### **MEDICAL ALERT FORM - GUIDELINES**

- Completed for people with life threatening or medically significant health issues. These may include but are not limited to: aspiration risk, fall risk, seizures, order for Diastat, history of bowel obstruction, significant allergies, cardiac issues, asthma or pain management concerns.
- Use good judgment and best practice; "If in Doubt, Fill it Out."
- Must be kept updated by the Nurse as conditions warrant.
- Prioritize and complete for people with the most significant or major concerns first.
- Completed form must be printed on bright green paper to be more visible and easier to locate.
- Completed form must be filed in the first page of the medication assistance record (MAR) or in the front page of the Shared Living Provider notebook.
- Copy of the completed form must also be sent for day service file.
- Form is to be reviewed as needed, but minimally at the time E-CHAT is completed.

Medical Alert

Any time there is a medical emergency call 911 immediately.

Name: \_\_\_\_\_ DOB: \_\_\_\_\_ Date: \_\_\_\_\_

Medical Concerns	Symptoms	Response

Name of Nurse: \_\_\_\_\_ Signature of Nurse: \_\_\_\_\_

The purpose of this form is to identify medical concerns that may be fatal or have serious consequences. Examples are Dehydration, Aspiration, Seizures, Constipation/History of Bowel obstruction, Diet modifications, Cardiac conditions, Asthma, Pain management and serious Allergies. It is to be placed in the individuals MAR.  
**\*\*\*THIS FORM IS TO BE USED IN CONJUNCTION WITH THE NURSING ASSESSMENT/ELP and SIGNIFICANT MEDICAL CONDITIONS. YOU ARE STILL RESPONSIBLE FOR ALL OF THE MEDICAL INFORMATION PRESENTED IN THESE ADDITIONAL DOCUMENTS.**

## Section 1 – Nursing Assessments

Section Name	Date Read/Completed	Initials
Electronic Health Assessment Tool		
Fall Risk Assessment		
Aspiration Risk Assessment		
Medical Alert Form		
Medical Alert Form Guidelines		

I, \_\_\_\_\_, have read and understood the  
(print name)  
information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had  
an opportunity to consult with my Supervisor and/or his/her designee and my questions have  
been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## Section 2 – Service Provider Health Education

### Health Promotion

The World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) in 2001. The ICF provides a standard language that you should use when discussing a person's health or when teaching. This will help accurately track health, functioning, activities, and factors in the environment that either help or create barriers for people. It is important for you to use and teach the correct terminology to the people you support, family members and direct support staff. The following terms and definitions were taken from the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF):

**Health Conditions** - refers to illness, disease, disorder, injury or trauma. The condition is usually a diagnosis. For example, autism spectrum disorders, spina bifida, and traumatic brain injury are health conditions.

**Body Structure** – refers to a part of the body. For example, heart, legs, and eyes are body structures.

**Body Functions** - describe how body parts and systems work. For example, thinking, hearing, and digesting food are body functions.

**Functional Limitations** - difficulty completing a variety of basic or complex activities that are associated with a health problem. For example, inability to move one's legs is a functional limitation.

**Activity** – refers to a task or action. For example, eating, writing, and walking are activities.

**Activity Limitations** - difficulty a person may have in doing activities. For example, not being able to brush one's teeth or open a medicine bottle are activity limitations.

**Participation** - being involved and fully participating in society. This means being included in all aspects of a communities' political, social, economic and cultural life.

**Participation Restrictions** - difficulty a person may have taking part in life situations.

**Environmental factors** - things in the environment that affect a person's life. For example, technology, support and relationships, services and policies are environmental factors.

**Personal Factors** - relate to the person, such as age, gender, social status, and life experiences.

## **DDDS Training Requirements**

Every employee of DDDS and contracting agencies is required to complete a series of trainings designed to provide an orientation to the DDDS and explain the function of DDDS and Delaware Health and Social Services (DHSS) in the lives of people who have developmental disabilities. These trainings also provide instruction to staff to assist them to appropriately support people and to help them stay safe.

Basic training requirements for ALL staff employed by DDDS and contracting agencies are outlined in the division's training policy.

## **Recommended Preventative Screenings**

The nurse shall promote the receipt of preventative health services, under the direction of the primary care provider. These services shall be in compliance with current standard medical practice as described by a nationally recognized professional or governmental medical organization. For people with developmental disabilities, screenings may be recommended more or less often, or at different ages depending on the person's unique circumstances. As the nurse working with people who have DD, you must assure that people receive vaccines, immunizations, and routine diagnostic testing and screening that are appropriate for their age, health, and family history as recommended by current best practices. The nurse shall ensure that all health screenings etc. as recommended /ordered by the health care provider are completed in a timely manner with appropriate follow up.

## Section 2 – Service Provider Health Education

Section Name	Date Read/Completed	Initials
Health Promotion		
DDDS Training Requirements		
Recommended Preventative screenings		

I, \_\_\_\_\_, have read and understood the  
(print name)  
information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had  
an opportunity to consult with my Supervisor and/or his/her designee and my questions have  
been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## Section 3 – MEDICATION & HEALTH REVIEW

### Guidelines

The Nurse is responsible for reviewing the medication records for all assigned individuals each month. The medication and health review for individuals in Shared Living is done each month as forms are received and when Quarterly Reports are due. A health review is completed for each person who lives in a neighborhood home at the time of the monthly review. Health reviews for residents of neighborhood homes require a response from the Program Manager within the time frame specified by the Nurse.

### Shared Living Progress Reports/Audits

The Nurse is responsible for contacting the Shared Living Provider (SLP) at least once a month, either by phone or in person. The Nurse must also visit the home at least once a year. During the home visit the Nurse will verify that medications are kept in a secure location and that the individual's medications are not mixed with medications of other household members. Medications that are considered "controlled medications" must be securely double locked. More visits may be necessary depending on the needs of the individual and at the discretion of the Nurse. All contacts will be documented by T-log in the electronic record.

Every time the SLP takes an individual to the doctor or dentist, they must take with them a *Medical Appointment Information Record* (MAIR) and/or a *Dental Appointment Information Record* (DAIR) form. Every month the SLP will send the Nurse forms for the previous month. It is the Nurse's responsibility to enter the information into the electronic record. Scan the document and save it in the individuals file. Enter the electronic record in the Shared Living section and go to appointments in the health tracking area. Fill in each area. Attach the scanned document to the appointment screen. When you are finished be sure to click on submit. If there are any medication changes, go to the medication section and either click on new to enter new medications or click on search and enter the person's name and check In Prep and Approved, then Search. You may then select the medication you need to change and enter the changes. You can go to the other modules and enter weights and vital signs if they are available. This information will then be available when you do the Quarterly report for the individual. Once finished with the form, send the original to Health Information Management (HIM).

If there is any type of incident with an individual in Shared Living, the provider is to call DDDS staff. If it is medically involved they should contact the Nurse and give full details. Such incidents might be a fall, a seizure or a medication error. After determining if any follow up care is needed the Nurse is required to notify the Nurse Supervisor and the DDDS Case Manager.



They will then complete a General Event Report (GER) or a Seizure report in the electronic record. Under GER click on new and fill out the report completely and submit it. In the Health Tracking section you will find the Seizure report. Click on this and answer questions as reported to you, then submit.

The Nurse is also responsible for tracking other health issues for the person in Shared Living in the electronic record by entering information obtained from the MAIR into the Health Tracking module. Information such as weight, blood pressure and Glucose can be tracked for the quarterly report. The Nurse must complete a quarterly report for each individual. This can be done by setting up a list of required information in the report section. Click on Health care report, select the information to be included in the report, select the three month time frame for the report, and the individual. Select Create Report. The report will appear, at this time you will name the report according to the month and year – for example “July to October 2013 Quarterly Report.” There is a section for comments at the bottom. If there are any issues this is where the Nurse will document them. Save the report again. You may then go back to the report and choose to send the report via Scomm to the day program or the Public Guardian. After completing the Quarterly report, bill for the time and make a t-log entry stating that it has been done and can be found in the Health Tracking Reports.

SLPs are required to fill out a *“Shared Living / Respite Monthly Medication Tube Feeding Record.”* This form is to be completed monthly and submitted to the Nurse by the 15<sup>th</sup> of the month for the previous month. For example, January’s form would be due by February 15<sup>th</sup>. The form must list each medication the individual is receiving, the dosage and how many times a day it is given. There are also columns for number of refills left and when it was refilled last. If an individual is receiving tube feedings, the information in section 11 must be completed as well. Once this is received, the Nurse will reconcile the medications with those listed in the electronic record. Enter the electronic record in the Shared Living section. Scroll down to the medications in the health tracking section. Click on search and follow directions as above. When the medication list comes up, compare each medication on the list to the one from the provider. Everything that does not match must be investigated for new orders or changes that have not been reported. If the Nurse is unable to identify the cause of the discrepancy, the health care provider must be called for clarification.

Any time a SLP is not meeting contractual requirements, such as missing appointments for the individual or not turning in paperwork, it must be documented. If the nurse does the review and finds that appointments are behind schedule, the provider must be contacted and notified of the need for improvement. This must be documented in the electronic record via T-logs as well as by notifying the individual’s DDDS Case Manager. If a provider persists in this behavior, a

*Notification of Failure to Meet Contract Standards* form should be completed and sent to the DDDS Office of Budgets, Contracts and Business Services (OBCBS)

### **Shared Living Provider Notebook**

The SLP notebook is put together by the DDDS Case Manager. The Nurse provides the MAIR, DAIR and Monthly Medication Record forms, usually 10 to 15 at a time. He/she will also provide the Annual Physical Exam (APE) and Standing Medication Order (SMO) forms when appropriate and a copy of the annual nursing assessment. If the individual has a diagnosis that warrants a Medical Alert Form, the nurse will provide that to be placed in the notebook as well.

### **Neighborhood Home/Community Living Arrangement (CLA) Audit**

The Nurse is responsible for reading T-logs and General Event Reports (GER) in the electronic record as close to daily as possible. This will give the Nurse an idea what is going on with the individuals in his/her caseload on a day to day basis. Neighborhood homes must be visited monthly. At the visit each person's medications, MAR and electronic record are reviewed. The most common issues found in the review of the home are related to medications. The staff working in neighborhood homes are required to complete a Delaware Board of Nursing approved course to learn how to assist individuals with their medications. The staff member who takes the person to the appointment might not be the one assisting with the medication; therefore the prescription and label instructions need to be very clear. Pharmacy labels must match the prescription exactly as written. Anyone coming in to work should be able to help with the medication and do it correctly based on the label. While still at the doctor's office the following must be verified:

1. Staff should make sure they can read / understand the orders before leaving the office.
2. Medication orders must be specific. Orders may not contain the word "or" as in 1 or 2 tablets; or give choices such as 4 to 6 hours.
3. Orders for topical medications must specify where to apply i.e. to rash in diaper area; to wound on bottom of right foot, etc.
4. If it should be taken at a specific time, it must be written on the script and MAIR.
5. Prescriptions cannot say PRN without explanation, i.e. apply ointment twice daily to groin area as needed for rash; take 1 tablet for constipation after 3 days of no bowel movement. The parameters must be clear so that everyone understands them and assists with the medication/treatment the same way.
6. When medicines are discontinued, staff must assure that it is written on an MAIR to discontinue a medicine for their records.

When reviewing medications, remember:

1. Everything MUST match. The MAIR must match the label and must also match the MAR.
2. Every open medication must have a start date indicated on it somewhere.
3. If a medication is not bubble packed, it must have a count sheet and it must be counted in accordance with current policies and guidelines.
4. If it is bubble packed, check from the start date to the current date and verify that all doses have been given and signed off.
5. If meds have not been given for some reason, they should be circled on the MAR, make sure the reason is documented on the back of the MAR.
6. Controlled medications must be double locked and counted every shift. Every shift in a neighborhood home is twice a day. (There is no day shift as residents are typically away from home during the day).
7. Check Standing Medication Order (SMO) medications for start dates and expiration dates.
8. If a doctor prints office notes electronically and they include medications, *it is considered an order*. If the doctor's list does not match the current list of medications, the Program/House Manager will need to resolve the discrepancy, usually by contacting the doctor's office to verify which list is correct.

When the Nurse is in the home and finds an ongoing medication error, it must be addressed before he/she leaves. If no one is in the home the Nurse must contact someone starting with the Program Manager and working up the agency's chain until someone is able to assist.

After reviewing the medications, the Nurse then reviews the electronic record. The nursing assessment, Significant Medical Conditions (Plan of Care), and Medical Alerts are checked for any changes that need to be made. The Nurse then moves on to the Appointment module of the electronic record. Check each medical specialty appointment for any new visit and to see if a visit should have been made and wasn't. Confirm any new orders have been transcribed and ordered. The Nurse should document in the electronic record any contact with Individuals, Providers, Staff, Day Programs, or other DDDS staff related to individuals on his/her caseload.

The Nurse uses the Medication and Health Review form in the electronic record for each individual in the home. In the ISP module the Nurse selects the home and then the individual, and then selects Monthly medication review. When it opens, the next step is to select the date and submit then enter the time. The location is the home being reviewed. The service provider must be changed; it will not accept your name at this point. Select "other" from the drop down list if your name is not found and then enter your name in the box provided. For each category following, the Nurse must select yes, no, N/A or action. Comments can be written in the area

provided. Every box must have a selection made or the report cannot be completed. There must be a comment at the end or the report cannot be completed. This is where a date for response can be given. After completing the report, hit save then at the top of the page select create report. On the next screen select the medication and health review and click next, then select that date as the start and end dates. When the report comes up, name it by the month and year and save again. Then select back to report from the top of the page and you will be able to send the report via S Comm to the Program/House Manager.

### **Provider Response**

The provider is required to review the report and respond to the Nurse by the specified date. The Nurse should receive an S Comm notification that the response is ready in the electronic record. At that time he/she should check to see that all concerns have been addressed.

### **Coordination, Advocacy, Monitoring of Appropriate Follow-Up & Resolution of Identified Clinical Needs**

The Agency/Provider is responsible for helping the person to select Physicians and dentists. They must help the person choose from those approved by their insurance or contracted by DDDS. The Nurse does not typically schedule the appointments. The staff at the person's home are the ones that know what fits into their schedules best. The Nurse also does not routinely attend appointments but may under special circumstances. These circumstances may be a potential new diagnosis of cancer, any serious condition which the provider feels they need help understanding, a condition which is not improving, etc. After appointments, the agency is responsible for scanning the MAIR into the electronic record along with any lab and radiology reports. The Nurse will review these as they come in as he/she does with those received from the SLPs. It is the Nurse's responsibility to advocate for the individual if he/she feels there may be an alternative treatment or the individual has increased physical needs. If anything stands out from any report, the Nurse should contact the provider to discuss it with them and determine if any further action is needed.

### **Referrals to Medical Specialists**

Physicians may refer people to medical specialists at any time. However, if the individual is insured by Medicaid, the support team can elect to refer the person to a specialist for care as well, provided there is a medical need and the provider accepts Medicaid as payment.

### **List of Contracted Professionals/Funding Guidelines**

DDDS maintains a current list of professionals with whom they contract for services not provided by Medicaid (i.e. dental). Contact the regional Nurse Supervisor or DDDS Case Manager to obtain a copy of this list and guidelines for funding.

### Section 3 – Medication and Health Review

Section Name	Date Read/Completed	Initials
Guidelines		
Shared Living Medication Logs		
Shared Living Progress Reports/Audits		
Shared Living Provider Notebook		
Neighborhood Home/ Community Living Arrangement(CLA) Audit		
Provider Response		
Coordination, Advocacy, Monitoring of Appropriate Follow Up and Resolution of Identified Clinical Needs.		
Referrals to Medical Specialists		
List Of Contracted Professionals/Funding Guidelines		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## Section 4 – Admission to and Transfer of Residential Services

### Admission from Family Home (Family Support)

#### Nurse's responsibilities when an individual is admitted to Residential Services:

- Attend Transfer Planning Conference (TPC) Meeting (Usually 30 days prior to admission); also attend pre TPC if scheduled. If individual has a DDS Family Support Specialist, ask Family Support Specialist for parents/caregivers contact information. Call parents/caregivers and tell them to bring medical records, list of current medications, immunization record, and etc. if possible.
- Take RN TPC Checklist, physical form, SMO, release of information, and MAIR to the meeting.

Obtain the following information from transferring nurse, parents, and/or caregivers.

1. Vital Statistics (weight, height, usual BP and pulse, etc.)
2. Diagnoses and medical history including communicable diseases
3. List of current medications (dosage, frequency, prescribing physician)
4. Current physician's addresses and phone numbers and any scheduled or needed appointments. Discuss if there is a need to establish any new practitioners.
5. Immunization information- inform caregiver/provider that 2 step PPD is required prior to admission
6. List of adaptive Equipment (how maintained, repair information)
7. Nursing Assessments and ELP (if one is in place or has been developed)
8. Individual Profile if individual is coming from Family Support
9. Obtain release of information so medical history can be requested/transferred
10. Discuss need for Physical, Occupational and Speech Therapy assessments and Audiology
11. Discuss supports the person needs for medical procedures (i.e. antibiotics prior to dental appointments, conscious sedation, etc.)
12. Discuss who will sign consent forms for medical/dental procedures.

*Individuals must have a current physical or comprehensive medical exam, 2- step PPD, and SMO form completed prior to admission. If this has not yet been completed, furnish current provider with instructions and necessary forms. Ask provider/ parents to bring as much medication as possible as well as prescriptions for all medications on the day of admission (at least a 2 week supply of medication).*

### **Nurse's Responsibilities Day of Admission**

- Complete Fall and Aspiration Assessments, document by T-log. Emergency Temporary Living Arrangement (ETLA) assessments must be done within 48 hrs.
- Review medical documentation
- Ensure appointments that are immediately needed are scheduled
- Count medications, complete medication transfer form, complete count sheet form for any medication not in bubble packs (neighbor homes only), document by T-log
- Obtain copies of prescriptions and ensure house manager or SLP sets up pharmacy account and turns in prescriptions to be filled. For Shared Living Providers, review expectations that monthly medication logs are due on the 15<sup>th</sup> of every month for the previous month (ex. March med log is due by April 15<sup>th</sup>).
- Ensure proper storage of medication.
  - In NH, each individual's medication should be labeled and separated from housemates and all medications locked. Controlled substances must be doubled locked. Internals must be separate from externals. When possible and practical, all medications should be requested in "bubble packs".
  - In a licensed SLP's home, medications for 2 or more individuals are to be separated and locked in a cabinet. Internals and externals are separate.
- Review MAR and treatment record for accuracy
- Start Health Records in Electronic Record.
- Weigh individual and document. Instruct staff to weigh individual weekly for first 30 days, document by T-Log.
  
- **Day of Admission Checklist- Neighborhood Home (ETLA done within 48 hrs)**
  - ☐ Complete fall and aspiration assessment day of admission or next business day
  - ☐ Ensure medications are counted, medication transfer forms are completed (transfers only), count sheets started on any medications not bubbled packed
  - ☐ Ensure proper storage of medications
  - ☐ Review MAR and treatment record for accuracy
  - ☐ Ensure appointments that are immediately needed are scheduled
  - ☐ Ensure Health Records are started in Electronic Record.
  - ☐ Ensure individual is weighed and documented. Instruct staff to weigh individual weekly for first 30 days and document.

### **Nurse's responsibilities within 30 days of admission**

- Ensure needed medical appointments are scheduled
- Ensure copies of physical exam form, SMO, current prescriptions are in COR or SLP notebook, obtain copies for Nurse's record. (annual physical and dental cleanings scanned into the electronic record; NH placement-agency responsibility; SL- DDDS Nurse responsibility)
- Ensure baseline assessments are scheduled (OT/PT, Speech, Audiology, GYN) as needed
- Complete and fax nutritional evaluation to Registered Dietician for all new admissions, document by T-Log
- Ensure appointments for needed immunizations including Hep B, Flu, and any others indicated are scheduled.
- Complete the Nursing Assessment and attend 30 day meeting, document by T-log. If individual is new to the Division, complete an Intake ELP Nursing Assessment. If the individual has an ELP from a previous placement, it should be updated at this time.

### **30 Day Post-Admission Checklist**

- ☐ Complete Nursing Assessment and attend 30 day meeting, document by T-log. If individual is new to the Division, complete an Intake ELP Nursing Assessment. If the individual has an ELP from a previous placement, update at this time.
- ☐ Complete and fax nutritional evaluation to Registered Dietician for all new admissions, document by T-Log
- ☐ Ensure needed medical appointments are scheduled
- ☐ Ensure copies of physical exam, SMO, current prescriptions/ physician's orders are in COR, give SLP copies for SLP notebook, and keep copies for nurse's record. (all MAIR/DAIR forms scanned into electronic record; NH placement-agency responsibility; SL- DDDS Nurse responsibility)
- ☐ Ensure baseline assessments are scheduled (OT/PT, Speech, Audiology, GYN) as needed
- ☐ Ensure appointments for needed immunizations including Hep B, Flu, and any others indicated are scheduled.



## Planned Placement Transfer Checklist

The Nursing Protocol listed below must be followed when transferring an individual from one residential placement to another. For ETLA this must be done within 48 hrs.

- Prior to the transfer planning conference (TPC) the transferring nurse shall review the medical components of the COR and is responsible for updating any issues.
- The following must be completed as part of the final Nurse review:
  - ✓ Physical - current or is scheduled
  - ✓ Medical Appointments - current or are scheduled
  - ✓ MAIR corresponds with MAR/ Monthly Med Logs
  - ✓ Document in T-log that all ordered testing has been completed or scheduled
  - ✓ Update or complete a Medical Worksheet listing dates and times of upcoming appointments for the receiving Nurse
  - ✓ Ensure ELP Nursing Assessment contains all current and relevant information
  - ✓ Nursing Assessment must be updated if ELP is scheduled one month or less after the transfer
  - ✓ Shared Living Provider (SLP) Notebook contains updated/current medical information.
    - ❖ SLP Notebook must minimally include:
      - Nursing Assessment
      - Medical Alerts
      - Fall Assessment
      - Aspiration Assessment
      - MAIR that documents medications ordered
      - SMO
      - Completed Physical Exam form
      - Information about required medical procedures, etc.
      - Medication Side Effects Sheet from pharmacy, physician, or printed from assigned DDDS nurse.
      - Blank Forms (MAIR, PAIR, DAIR, and Monthly Med log)
      - Immunization Record
      - Miscellaneous Data Record (seizures, Accuchecks, falls, etc.)
      - Nutritional Evaluation/ Dietary Guidelines
      - Standard Precautions

#### Section 4 – Admission and Transfers

Section Name	Date Read/Completed	Initials
Admission From Natural Family		
Day Of Admission Checklist		
30 Day Post-Admission Checklist		
ETLA(Emergency Temporary Living Arrangement)-Checklist		
Planned Placement Transfer Checklist		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## **Section 5 – Assistance with the Self-Administration of Medication**

### **Assistance with Self Administration of Medication**

#### **Guidelines**

In order to assist an individual being supported by the Division of Developmental Disabilities Services (DDDS) with their medication(s), staff must successfully complete all sections of the DDDS Assistance with Self Administration of Medications (AWSAM) Program. All newly hired staff must complete the two day class with the required supervised field medication pass observations. Thereafter, successful completion of the recertification class is required annually.

There will be handouts distributed to all trainees no more than seven (7) days prior to his/her scheduled two day or recertification class. The handouts are not to be present when completing the College of Direct Support AWSAM Module. The trainee must provide a picture identification to participate in any of the AWSAM classes.

#### **Two Day Class with Supervised Field Medication Pass Observations**

##### ***Day One***

Day one will consist of classroom instruction with a registered nurse who has been approved by the Delaware Board of Nursing as an AWSAM instructor. An overview of medication safety, transcription of practitioners' orders, medical appointments, along with other pertinent information for the safe assistance with self administration of medications will be included. The classroom instruction will include instruction of oral, optic (eye), topical, otic (ear), and rectal routes of administration along with a return demonstration by the participants. The participants must correctly complete the return demonstrations to successfully move on to day two.

***Day One and Day Two must be completed on consecutive days.***

##### ***Day Two***

(This will be in a proctored setting and all lessons shall be completed during one session. There will be no electronic devices permitted in the area when completing these lessons. The proctor must be in a supervisory position within the agency.)

Participants will complete the seven (7) medication lessons within the College of Direct Support. The DDDS AWSAM Program requires participants to complete a test following each lesson with a proficiency of 80% or better. If a participant fails any module, they may retake the lesson one (1) time.

Failure to successfully complete these requirements will result in the participant having to retake the two day course. If the participant fails a second time, he/she will not be permitted to assist any individual with medications. The participant may retake the two day course after six (6) months with recommendations from his/her supervisor that he/she is prepared to retake the course.

### ***Supervised Field Medication Pass Observations***

Participants must successfully complete 10 observed medication passes in the field after the successful completion of Day One and Day Two.

The observed field medication passes are designed to give a trainee the opportunity to practice the application of the information that they have learned in the classroom. The field pass is an exercise for the trainee and it serves as an opportunity for the authorized observer to share his/her knowledge and expertise with the trainee. In order for this process to be effective, it requires feedback from the authorized observer and verbal cueing from the trainee. The trainee should state each step out loud as it is being performed. This will assist in committing the steps to memory and also in ensuring that all steps are followed according to procedures.

The authorized observer's signature on the medication pass checklist declares that the process occurred correctly. If it is determined that an error occurred during this process, the authorized observer doing the observation will be held equally accountable as the trainee for the medication error. Therefore, it is imperative that all involved understand the seriousness of this process. In some instances, errors can be considered neglect and could result in a criminal investigation, charges and/or fines. Inadequate supervision during the assistance with medications can result in the loss of life. It is important that everyone participating in this process use caution and care.

A medication pass is defined as assistance that is provided during one medication assistance time. The number of individuals for whom assistance is provided or the number of sites in which assistance is provided is irrelevant. A trainee can only receive credit for the completion of one medication pass per medication assistance time (no exceptions). This observation will constitute a single medication pass. Successful completion of 10 supervised field medication passes is required. Remember, the purpose of supervised passes is to help the trainee become familiar with the entire medication program, from start to finish.

For example, a 3 – 11 shift with "PM" and "HS" medication assistance times would provide the opportunity for 2 observations to be completed. A successful field medication pass must include correct execution of the steps, proper documentation and adequate follow-up. Field Medication passes must be completed within 60 days of the course work (Days 1 and 2) or the trainee will have to repeat the basic AWSAM course.

Upon the successful completion of 10 supervised field medication passes the trainee will obtain an authorization (final voucher) from their Agency's designee to assist with medications without direct supervision. The Agency is responsible for ensuring that there is a system in place to monitor the on-going performance and supervision of the field medication passes occurring in all of its programs.

The DDDS Office of Quality Improvement will confirm that all vouchers (classroom, College of Direct Support, and practicum) are present during audits, as evidence of the authorization to assist without direct supervision during the assistance with medications.

#### **Authorized Observers:**

In order to be authorized to observe during a field medication pass and sign the supporting documentation, one of the following provisions must be met. It should not be rushed or done haphazardly.

- I. The Observer is an employee with the Division of Developmental Disabilities Services (DDDS) or a DDDS contractor with a minimum of 2 (two) years of experience. These individuals shall have no history of medication errors over the past 2 years and shall have a current voucher from the Assistance with Self Administration of Medication class; or
- II. The Observer is a supervisor with DDDS or a DDDS contractor, at least at a Program Manager or Program Coordinator level with a minimum of 6 (six) months of experience. These individuals shall also possess a current voucher in the Assistance with Self Administration of Medication Class; or
- III. The Observer currently holds a valid state of Delaware Nursing license, has attended the two day Assistance with Self Administration of Medication class through DDDS, and has worked within the DDDS system for a minimum of 3 (three) months.

#### **Recertification:**

(This will be in a proctored setting and all lessons shall be completed during one setting. There will be no electronic devices permitted in the area when completing these modules. The proctor must be in a supervisory position within the Agency.)

Participants will complete the seven (7) medications lessons within the College of Direct Support. The DDDS AWSAM Program requires participants to complete a test following each lesson with a proficiency of 80% or better. If a participant fails any lesson, they can retake the lesson one (1) time.

If a participant fails a second time, they will then be required to attend the two day class (excluding the supervised medication passes). If the participant then fails the two day class, he/she will not be permitted to assist any individual with medications. The participant may retake the two day course after six (6) months with recommendations from his/her supervisor that he/she is prepared to retake the course.

Direct Support Professionals shall be scheduled to complete recertification every eleven (11) months. This will allow time to retake any requirement(s) that the candidate did not successfully complete during the first attempt before his/her AWSAM authorization expires.

**DOCUMENTATION:**

All Agencies will maintain the voucher for the coursework, the practicum review sheet and the Agency authorization as evidence of compliance with the Delaware AWSAM Program.

**Pharmacy Label Changes**

ONLY the Nurse or another licensed healthcare professional is permitted to change a pharmacy label and then only with orders from a Physician or other individual legally able to prescribe medications.

## Section 5 – Assistance with the Self Administration of Medications

Section Name	Date Read/Completed	Initials
Assistance with Self-Administration of Medication (AWSAM) Training Program		
Phase 1		
Phase 2		
Guidelines for Phase 2		
Authorized Observers		
Pharmacy Label Changes		

I, \_\_\_\_\_, have read and understood the  
(print name)  
information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had  
an opportunity to consult with my Supervisor and/or his/her designee and my questions have  
been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## **Section 6 – Policies, Protocols and Forms**

### **DDDS POLICIES**

DDDS policies are divided into 2 categories; Administrative policies and Community Services policies. Each respectively governs the activities of the Administrative Officers of DDDS and of Community Services staff. Although all DDDS policies apply to all DDDS and contracting agency staff at all times, there are some policies that are of particular interest to clinical staff. In this section, an over-view of the most relevant policies for Nurses is provided.

#### **Abuse & Neglect (Administrative Policy)**

This policy outlines the standardized procedures for responding to allegations of abuse, assault, attempted suicide, neglect, mistreatment, financial exploitation and significant injury. Standardized procedures are established by this policy for reporting, investigation and follow-up. ALL DDDS staff and contractors who have reason to believe that any type of aforementioned abuse has occurred are required to take the following measures:

- Take action to treat, protect and comfort the individual(s) involved
- Ensure that victims of alleged sexual assault are examined by a Sexual Assault Nurse Examiner (SANE) at the hospital
- Contact police to report criminal activity and protect the crime scene as necessary
- Report events to the regional PM#46 Coordinator (for Community Services) or the Executive Director of Stockley Center
- If the PM#46 Coordinator cannot be reached, contact the DDDS on-call number
- Make a verbal report to the Division of Long Term Care Residents Protection (DLTCRP) by calling the 24-hour toll free number: 1-877-453-0012

#### **Assistance with Self-Administration of Medication (Community Services Policy)**

This policy sets forth the guidelines by which unlicensed healthcare professionals (direct support staff) may assist a person with medications or medical treatments. It is the policy of the Division that ONLY staff members who have completed the required classroom and practicum instruction may assist an individual with the self-administration of his or her medications or medical treatments. Unlicensed staff members must complete a 2-day initial training, a specific period of on-the-job supervised practice, and then must attend an annual re-certification training. Nurses holding a valid Delaware license are required to take the initial 2-day AWSAM training but are not required to take the annual re-certification training as long as their Nursing license remains current.



## **Communicable Disease Policy (Community Services Policy)**

The Communicable Disease Policy provides guidelines for reporting of communicable diseases. When a staff member becomes aware that a person has or may have been exposed to a communicable disease, they are required to report it to the Nurse or the DDDS on-call designee. The Nurse, along with the Nursing Supervisor, should review the specifics of each case to ensure appropriate clinical follow-up and that proper infection control measures are implemented. The Nurse Supervisor shall contact the Division of Public Health to ensure proper notification and reporting of communicable disease. If training is needed by staff, it is the Nurse's responsibility to make sure it is completed, either by a health care practitioner or the Nurse or designee.

## **Consent (Administrative Policy)**

This policy establishes standards for the protection of the rights of individuals receiving services with respect to programming and treatment options. Consent of the person receiving services must be obtained for any activity or procedure that presents a significant risk to the individual or has a potentially irreversible impact or is physically, psychologically or socially intrusive.

Consent for treatments recommended by a service provider will be processed using the guidelines of this policy. In some cases, the Nurse will need to be involved in this process.

Consent must be obtained for the following:

- Participation in experimental research
- Release of information from the person's records to a currently unauthorized individual
- All behavior modification programs where restraints, time out or aversive stimuli are used
- Use of drugs which modify behavior (pursuant to DDDS policy)
- HIV testing (as required by Delaware code)
- All activities and programs where consent is required by another policy
- Contracts involving payment or exchange of services
- Medical treatment/elective surgery/diagnostic procedures
- Admission to programs (residential, day programs)
- Educational programming
- Legal representation

Unless otherwise specified by DDDS policy, if services are proposed by the community physician or other medical professionals, the Nurse shall be "the person initiating a procedure/activity which requires consent" and is responsible for assuming that role in the process of obtaining consent from/for the person.

## **Consent for Elective Surgery (Administrative Policy)**

For individuals who do not have the ability to give informed consent (as specified in Title 16 Del. C. §5530 – 5531) for medical or dental treatments, the DDDS has established the “Consent (Elective Surgery) by Division Director/Designee” policy. This policy establishes standards and procedures for obtaining informed consent from the Division Director or designee for individuals without a guardian who are receiving residential services from the DDDS and/or contracting agencies.

## **Death of an Individual (Community Services Policy)**

When a person receiving services from DDDS dies, there is a standardized process which must be followed. These procedures are outlined in the Death of an Individual (Response to) Policy. It is the responsibility of the DDDS Case Manager to coordinate burial plans with the individual’s family. However, there are some specific things the Nurse must do when someone dies. According to this policy, the Nurse must be notified when a person receiving services dies, whether in the care of a Residential Agency, a Shared Living Provider or other In-patient Facility. Within one (1) working day of receipt of notice, the Nurse Supervisor or designee MUST:

- Secure and audit all of the individual’s medications, both prescription and non-prescription
- Document findings in an ID note or T-log. If there is a discrepancy, explain it to the best of his or her knowledge in the documentation
- Consult with the Regional PM #46 Coordinator to determine if there is any on-going investigative activity related to the death
- IF there is ongoing investigative activity related to the death, transfer unused medications to the Regional PM #46 Coordinator. The Nurse must document the transfer of this evidence on the Medication Chain of Evidence form (attached to this policy)
- IF there is no investigative activity related to the death, the Nurse will dispose of any unused medications in accordance with policy, in the presence of a witness, and document this activity in an ID note or T-log

## **Health Care Service Policy (Community Services Policy)**

This policy sets forth guidelines to ensure that people receiving supports from DDDS and contracting agencies receive health care services that promote good health and well-being. This policy establishes uniform standards of practice for DDDS Nurses, Nurses employed by contracting agencies and Shared Living Providers

It is the responsibility of the person's entire support team to ensure that they receive appropriate, timely and quality health care services. DDDS and contract agency Nurses are charged with promoting the receipt of preventative healthcare services, under the direction of the primary care provider, in compliance with current standard medical practice.

The DDDS Nurse serves as the primary health care advisor for people in Shared Living and other residential situations where a contracted Nurse is not required.

In cooperation with contracting Nurses, The DDDS Shared Living Coordinator, the DDDS Office of Training and Professional Development (TAPD) and the DDDS Office of Quality Management (OQM), DDDS Nurses are responsible for ensuring that Shared Living Providers and agency staff are trained to assist an individual with his or her medications and/or medical treatments according to DDDS policy and as required by the State Board of Nursing.

DDDS Nurses and contracting Nurses also provide guidance regarding pharmacy services when issues arise.

### **Health Related Protection (Community Services Policy)**

This policy establishes standards and procedures for the use of health related protections where the person's safety is at risk.

A health related protection, as defined by this policy is any material or mechanical device or equipment used to restrict the movement of a person so as to prevent fall or injury. Examples of mechanical equipment that might be used to prevent fall or injury are: bed rails, bed enclosure systems, seat belts other than in a vehicle, etc.

This policy also establishes the presence of the Health Related Protection Committee which reviews requests for the use of these types of measures. All health related protections must be ordered by a licensed healthcare practitioner prior to implementation. As part of this process, the Nurse may be asked to complete or provide assessments as justification for the health related protection.

### **PROTOCOLS & GUIDELINES**

In addition to the Administrative and Community Services policies that govern the activities of the DDDS and its affiliate agencies, DDDS has developed for use a series of protocols that provide information about best practices in Nursing as they relate to providing support to people who have developmental disabilities. In this section, an overview of the current DDDS protocols for Nursing is provided.

## **Aspiration Protocol**

This protocol sets forth guidelines for assessing people who may be at risk of aspiration or choking. Individuals coming in to residential services are assessed, and those at risk are assessed every year after to coincide with their annual Essential Lifestyle Plan (ELP). The Nurse is responsible for completing this assessment. Individuals who have a change in health status must be assessed any time during the year the need is present.

If an individual is assessed to be in the moderate or high risk category, the regional DDDS Nursing Supervisor, or the Contracting Agency Nurse Supervisor must be notified and steps taken to immediately ensure the safety of the person. This must also be included in the person's ELP under the "Significant Medical Conditions" heading of the ELP Nursing Assessment, or on the ECHAT.

## **Constipation Protocol**

Constipation is a condition that often goes unrecognized because people with disabilities may not be able to indicate when they are not feeling well until it poses a major health problem. This protocol outlines the Nurses responsibility in helping staff to watch for, prevent and treat constipation and bowel issues for people they support.

If a person is diagnosed with constipation, or has a history of impaction/bowel obstruction, or is at a high risk for elimination concerns because of another diagnosis, medication or treatment or is exhibiting symptoms, the Nurse will instruct the person and/or his or her support staff what symptoms to watch for and how to record bowel eliminations. The Nurse will also instruct staff as to when/how to report changes or concerns and when to seek immediate emergency treatment. When instruction is provided to staff the Nurse should document this activity in an ID note or T-log.

## **Dental Services Protocol**

When dental care is neglected, it can lead not only to tooth decay and gum disease, but to other significant health problems as well. This protocol outlines responsibility to ensure that people get appropriate and fiscally responsible dental care.

There is a Contract Manager in each region that is assigned to over-see contracted dental services so as to maximize funds and provide support to as many people who need it as possible.

The Nurse assigned to each individual will receive the Dental Appointment Information Record (DAIR) as soon as possible after each dental visit. The Nurse must review the form and, if

conscious sedation/anesthesia is needed or if the person requires treatment not considered routine, the Nurse must immediately forward the form to the Contract Manager.

The Nurse may be responsible for teaching the person and/or his or her support staff how to provide proper dental care. Attached to this protocol are training tools the Nurse might utilize.

### **Diastat Protocol**

Diastat is a medication that comes in a pre-packaged rectal delivery system and is used to stop prolonged seizures and clusters of increased seizure activity. It works much more quickly than oral medications and is much easier to give than IV diazepam. It has been shown to begin having an effect in as little as 5 – 15 minutes. Diastat is intended and approved for use by non-licensed healthcare professionals (direct support staff). Prior to beginning use of Diastat, all direct support staff members who might need to assist with it, as well as the person and his or her Guardian or other authorized advocate must be instructed in its use, and consent must be obtained. It is the responsibility of the Nurse to make sure that the person and his or her Guardian or advocate are given enough information to enable them to give informed consent for the use of Diastat.

If Diastat is prescribed for an individual, those staff members who accompany the person to medical appointments must take with them a copy of the Diastat Order Form. This form must be completed by the prescribing healthcare professional and a copy should be faxed to the Nurse as soon as possible after the appointment. Within 2 days of receipt of the order for Diastat, it is the responsibility of the Nurse to ensure that all program sites (residential, day program, etc.) receive on-site training. It is also the responsibility of the assigned Nurse to complete an “Individual Diastat Protocol” form (attached to this protocol). Following prescription of Diastat, documentation that includes 1) actual episodes when Diastat was given and 2) related Emergency Department visits will become part of the regular Nursing documentation. At the time of the on-site training, the Nurse will verify the Diastat dosage and readiness of the AcuDial delivery system.

### **Enterostomy Protocol**

People are generally prescribed an enterostomy tube (a medical device placed into the stomach or small intestine via a surgical procedure) for feeding, hydration or receiving medication. For these people, proper care and maintenance is critical. The Delaware Board of Nursing advised the DDDS that Shared Living Providers can be considered to have the same eligibility to participate in providing this type of care as any other eligible family member.

The Shared Living Provider must be evaluated by the Regional Program Director and the Regional DDDS Nurse Supervisor as to their ability to provide appropriate care. The provider’s capability, interest, resources, etc. will be evaluated to determine their ability to meet the needs of the person.

To provide this type of support to a person in a Shared Living residential placement, the Shared Living Provider MUST:

- Possess a current Assistance with the Self-Administration of Medications voucher and one year experience
- Possess a current CPR and First Aid certification
- Demonstrate the ability to count and record respiratory and pulse rates
- Successfully complete a “Feeding, Hydration, General Knowledge, and/or Medication Assistance via Enterostomy Tube” return demonstration using the appropriate Competency Evaluation Tool
- Repeat the return demonstration each year

The Nurse will provide training to the Shared Living Provider about the use and care of the enterostomy tube. The training must contain the following components:

- General over view of how the administration of medication through the enterostomy tube relates to “Assisting with the Self Administration of Medication”.
- Purpose of the enterostomy tube
- Over view of different kinds of enterostomy tubes
- Over view of the different methods of tube feeding (bolus, continuous, intermittent)
- The importance of clean technique and how to clean equipment
- Proper maintenance of enterostomy tubes
- General positioning issues as well as positioning relative to the person’s specific needs
- Over view of the signs and symptoms of problems with enterostomy tubes
- How to prepare different forms of medications for use with the enterostomy tube
- Consideration of residual check maintenance
- Safe management and storage of formula and equipment
- Individual-specific training relative to all of the above including on-site return demonstration by a Registered Nurse, verified with the “Competency Evaluation Tool” attached to this protocol

## **Fall Management Protocol**

The Fall Management Protocol outlines procedures for identifying people who may be at risk for falls and for helping to keep them safe and protect them from injury.

When a person is admitted to residential services, as part of the pre-admission process a Fall Risk Assessment will be completed by the Nurse. The Fall Risk Assessment is repeated annually to coincide with the person’s ELP meeting. If an individual is determined to be at risk for falls, a fall prevention plan, specific to the individual will be a part of the annual Nursing documentation related to the ELP. Fall prevention plans include, at a minimum; needed education, physical, medical and environmental factors.

Falls shall be reviewed by the assigned Nurse any time there is an injury that results in the need for medical care or any time there are two falls (even if they do not require medical care). An important step in reviewing the fall is trying to determine why the person has fallen. At the Nurse's request, the Nursing Supervisor may order an assessment by a physical/occupational therapist.

The DDDS's Risk Management Committee regularly receives and reviews data on falls in an effort to identify significant trends and enhance safety.

### **Immunization Protocol**

To reduce the occurrence of preventable diseases and to protect the health of people receiving services from DDDS and the community, DDDS has enacted the "Immunization Protocol". This protocol was put in place to provide guidance to effectively protect people receiving services and others in the community from certain communicable diseases. Each individual's immunization status must be reviewed AT LEAST annually by the Nurse. The Nurse will assess the individual's status and eligibility for immunization based on the following factors:

- Age
- Immunization status (see CDC Guidelines or the current DDDS Immunization Protocol for health screening & immunization schedules)
- Presence of a medical condition that makes the person "high risk"
- Known history of allergy or reaction to immunization
- Place of residence

### **Management of Methicillin Resistant Staphylococcus Aureus (MRSA) Protocol**

This protocol has 2 objectives: 1) to outline infection control practices to prevent and/or control the transmission of MRSA and 2) to serve as an information resource for staff.

A review of infection control guidelines to help reduce or prevent the transmission of MRSA and other infectious conditions is outlined in this protocol. Included is information pertaining to hand washing, personal protective equipment, personal care services, wound care, and environmental considerations.

MRSA is considered a reportable communicable disease and is covered under the guidelines and standards of the DDDS Communicable Disease Policy. Any suspected incidence of MRSA must immediately be reported to the Nurse. The assigned Nurse, with the Nursing Supervisor and the State Nursing Administrator will review specifics of each case and assure that appropriate infection control measures are implemented and to assure proper follow-up.

## **Nutrition Management Protocol**

The purpose of this protocol is to effectively and efficiently promote and monitor nutritional health and safety for people receiving services.

- A.** The Registered Dietician (RD) will complete a Nutritional Assessment on all individuals upon admission to the Division of Developmental Disabilities Services (DDDS).
- B.** Annually, a nutritional screening will be performed by the Nurse Consultant for all individuals. The screening will be part of the Electronic Comprehensive Health Assessment Tool (eCHAT). During this review, if the nurse deems it necessary, a referral to the RD will be completed.
- C.** An individual can be referred to the RD anytime if the nurse deems the individual's health status warrants. Also, at the request of the individual, family, guardian, or health care provider, the Nurse Consultant can complete a referral to the RD
- D.** Nutritional status will be discussed by the interdisciplinary team with the individual and their advocates/family at the time of the Annual ELP. Outcomes of that process shall be documented in the ELP.

## **Self Administration of Medication Protocol**

The Self Administration of Medication Protocol has two objectives. The first is to provide a way to assess the skill and ability of people receiving services to administer their own medication unassisted and the second is to support independence for individuals wishing to administer their own medications or medical treatments.

When a person expresses a desire to be able to administer their own medications, or a member of his or her support team makes the determination that the person may be capable of administering their own medications, a meeting with the support team must be held to discuss the assessment and training process.

The Nurse will complete the Self Administration of Medication Assessment Form (attached to this protocol) to determine the person's readiness and ability to administer their own medications. If the Nurse's assessment concludes that the person has the skills necessary for this task, a self-medication training program will be implemented.

For people who are able to administer their own medications, the Nurse will include information in the ELP Nursing Assessment or the ECHAT indicating "supports needed for taking medication" and describing what parts the person does, what parts of the process must be completed by staff and how this process is monitored.



The Nurse must complete a new Self-Administration of Medication Assessment form to coincide with the person's annual ELP meeting, or whenever there is a decline in skills for the person.

### **Lithium Guidelines**

Lithium is often used in the treatment of bi-polar disorder. The full effect of the drug can be seen by 2 to 3 weeks after beginning use. Regular monitoring is necessary to ensure adequate serum levels and minimize the risk of toxicity. Different preparations of Lithium may vary widely so the same brand of Lithium should always be prescribed. Care should be taken and additional monitoring is necessary if changing between brands or between tablets and liquid is necessary.

Lithium toxicity is not uncommon in individuals with developmental disabilities. Signs of toxicity include:

- Blurred vision
- Increased gastrointestinal disturbances
- Muscle weakness
- Drowsiness
- Sluggishness
- Ataxia (a lack of muscle coordination which may affect speech, eye movements, the ability to swallow, walking, picking up objects and other voluntary movements)
- Coarse tremor
- Lack of coordination
- Dysarthria (trouble with speaking which can affect eating or breathing)
- Confusion
- Convulsions

Lithium should never be discontinued abruptly without consulting the prescribing doctor.

### **REQUIRED FORMS**

In this section is a brief description of forms that are typically required of Nurses working with and for DDDS. Most of these forms can be found on the DDDS website:

[http://www.dhss.delaware.gov/dhss/ddds/nursing\\_forms.html](http://www.dhss.delaware.gov/dhss/ddds/nursing_forms.html)

They can also be found attached to the various policies to which they pertain. In addition, many of the forms can be obtained from the DDDS Case Manager if there is a need. Although this section does not describe all the forms a Nurse may be required to utilize, it provides an over view of the most common forms and their use.

## **Adult Physical Examination (APE) Form**

Typically referred to as the “Physical”, this form is to accompany a person receiving services to his/her Physician to be completed prior to residential service admission and/or each year at the person’s annual physical examination appointment. It must be completed by the person’s Physician or designee and the most current form should be attached to the person’s ELP

## **Aspiration/Choking Risk Assessment**

This form is completed by the Nurse prior to a person’s admission to residential services, and annually in preparation for the person’s Essential Lifestyle Plan update. This form may be completed as needed when a risk is identified and/or the person’s health status changes.

## **Controlled Substance Count Sheet**

Because of the potential for abuse, regulations require that all medications in Schedules II – V (controlled medications) be double locked and counted (reconciled) at least once during every shift. The Controlled Substance Count Sheet is the record of how many controlled medication units should be on the premises at any given time.

## **Dental Appointment Information Record (DAIR) Form**

This form is should be taken with the person each time s/he visits the dental care provider and is completed by the person’s dental care provider and attached to the ELP. This form should be completed each time the person sees their dental care provider (every six months or as recommended by the provider)

## **Fall Risk Assessment Form**

This form is completed by the Nurse prior to a person’s admission to residential services, and at least annually in preparation for the person’s ELP update. This form may also be completed more often in response to an identified need (2 or more falls) or as health status changes.

## **Medical Appointment Information Record (MAIR) Form**

The Medical Appointment Information Record (MAIR) should accompany the person to every physician’s appointment and is completed by the physician or other health care practitioner at the time of the visit. This form serves as a record of the visit and of recommendations made by the physician. Page 2 of this form outlines for staff accompanying the person the reason for the visit, symptoms present, how long the symptoms have been present, what has been done for these symptoms in the past. It also provides staff a set of questions to ask the practitioner before leaving the office.

## **Medication Count Sheet**

All medications not in bubble packs require the use of a Medication Count Sheet. This form enables staff to record the number of units on hand, how many were administered at any given time, and the number of units remaining. Discrepancies must be reconciled as soon as they are discovered.

## **Medication Form for Leave/Vacation**

When a person is going on vacation or some other type of leave from their Neighborhood Home or Shared Living Provider's home, a Medication Form for Leave/Vacation should be completed. This form serves to document the number of medication units that were sent with the person, and the number of medication units that were returned with the person. It can also be used to provide specific instructions regarding medications or medical treatments.

## **Notification of Failure to Meet DDDS Contract Standards Form**

When a service provider fails to meet contractual standards, a Notification of Failure to Meet DDDS Contract Standards Form is completed and issued to the Provider and a copy sent to the Regional Program Director and/or the Nurse Supervisor. The form will list specific deficiencies and will give a specific date by which the Provider must come into compliance with contractual standards. Failure to adhere to contract standards could result in suspension or termination of a Provider's contract with DDDS.

## **Nutrition Referral Form**

When someone has a need for nutritional consultation, either due to weight loss/gain or a specific illness or condition, a Nutrition Referral form is completed and forwarded to a Registered Dietician under contract with DDDS. The Nutritionist will meet with the person for whom the referral was made and develop a nutritional plan or set of guidelines to help assure that the person receives adequate support around their specific nutritional requirements.

## **Psychiatric Appointment Information Record (PAIR) Form**

Similar to the MAIR, the Psychiatric Appointment Information Form (PAIR) must accompany the person to every psychiatric visit and be completed by the Psychiatrist or Psychologist treating the person. It will outline medications the person receives, recommended treatments or procedures and necessary follow-up appointments.

## **Psychology Department Referral Form**

When a person receiving services or their support team determines a need for support from a Behavior Analyst (BA) or Psychological Assistant (PA) a Psychology Department Referral form will be completed by a member of the support team, usually the Case Manager, and forwarded to the BA Supervisor within DDDS. A BA or PA will be assigned to evaluate the need for services and, if warranted, a BA or PA will be assigned to assist the person.

## **Standing Medication Orders (SMO) Form**

Each person receiving residential services must have in their record a completed Standing Medication Order (SMO) form. The form must be updated at least once a year by the person's physician or the physician's designee. This form is used to indicate what medications/treatments the physician prescribes for the treatment of relatively minor health issues such as headache, slight fever and minor abrasions. This form provides instruction as to how to monitor the use of these medications/treatments and when to seek further assistance from a medical professional.

## **Transfer Planning Conference (TPC) RN Checklist**

This checklist assists the Nurse to ensure that all necessary information is received or requested when someone is admitted to, or transfers between, residential services. It also serves to remind the Nurse of referrals that may need to be made or appointments that may need to be scheduled.

## Section 6 – Policies, Protocols and Forms

Section Name	Date Read/Completed	Initials
DDDS Policies		
Protocols & Guidelines		
Required Forms		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## **Section 7 – Nurse’s Role on the Support Team**

No matter what type of meeting you may be attending, your primary responsibility is to ensure that the person you are supporting receives the quality healthcare they want and need. In this section is a listing of some of the different types of meetings the Nurse working with DDDS may be asked to attend or for which the Nurse will be asked to provide input.

### **Essential Lifestyle Plan (ELP)**

The Essential Lifestyle Plan (ELP) is the State’s plan of care for each person receiving services. The purpose of the ELP is to provide information to support team members about the services the person wants and needs and how the person wants to live their life. The ELP also outlines Medicaid-funded services and community supports. The ELP must be updated at least annually and requires the input of all the support team members.

As part of the ELP planning process, the Nurse must complete the necessary assessments, and the ELP Nursing Assessment or ECHAT in advance of the ELP meeting so that the results of the assessments can be included in planning. The Fall Risk Assessment and the Aspiration Risk Assessment are a couple examples of the assessments that will need to be completed prior to the ELP. Whether using the ELP Nursing Assessment or the ECHAT, the Nurse will clearly describe the person’s health issues and what supports are needed, while taking into consideration the person’s expressed preferences, goals and life-style choices.

At the ELP meeting, it is also the Nurses responsibility to make sure that whatever other supports are enacted for the person, they take into account what the person needs in order to be healthy and well. For example, the person might express a desire to get a job. It would then be the Nurse’s responsibility to inform the person and the team about possible supports that might be needed relative to healthcare while the person is at work. If the person has Diabetes, the Nurse may suggest that there needs to be a mechanism in place to monitor the person’s blood sugar at work and to make sure they eat every 3 – 6 hours as recommended by the physician or the nutritionist.

### **Team Meetings**

It is required that each person supported by DDDS have an annual (within 365 days) ELP meeting. For many people, this is all that is necessary. For others, it may be necessary for the support team to meet more regularly due to on-going issues. A person may have a change in circumstances that will necessitate more regular meetings until it is resolved, or the person may develop new or worsening medical conditions that require closer monitoring by the team. At team meetings, it is the Nurse’s responsibility to inform the team as to the best practices in health care for the individual as well as how health issues and concerns may impact planning and resolution efforts. The paper-work required for each team meeting will differ depending on the issues.

## **Emergency Team Meetings**

If an emergency arises, it may be necessary for the support team to meet as a whole to address the issue. Some of the types of events that might necessitate an emergency team meeting include; accident or sudden illness, significant injury, involvement with law enforcement or admission to or discharge from an in-patient treatment facility. Whatever the reason for the emergency meeting, the Nurses responsibility will be to inform the planning process relative to the specific health concerns of that particular individual and to ensure that best practice with respect to health care is incorporated into planning efforts.

## **Transfer Planning Meetings**

When a person is transferring into a residential placement, or between residential placements, it is the Nurse's responsibility to make sure that all assessments are completed as required and that planning efforts and activities include consideration for the unique health care needs of the individual. It is also the Nurse's responsibility to ensure arrangements are made for continuity of care so that all health concerns are continually monitored and supported throughout the transition process.

The duties of the Nurse will vary depending on where the person may be coming from and the type of residential placement into which they may be moving.

## **Facility Discharge Meetings**

When an individual is being discharged from an in-patient facility, the Nurse should attend the discharge meeting. Nurses have a unique perspective in the team process and will be able to ensure that plans are in place to address health concerns throughout the process of moving out of the facility. The Nurse's responsibility includes making sure that staff who will be receiving the person into their new environment have adequate instructions to continue providing quality health care to the person as well as ensuring that needed items will be available for the person (i.e., medications, medical equipment, treatments, therapies, etc.).

## **Attending Medical Appointments as Appropriate**

In the majority of cases, the person's residential support staff will accompany them to medical appointments. Staff members are required to provide the correct form depending on the type of appointment and ask the health care practitioner to complete it for the person's record. Following the appointment, the form (or forms) will be added to the person's record. The Nurse should review these forms as soon as possible after the appointment to ensure there are no contradictions in terms of care or medications/treatments.

Some of the forms the Nurse can expect to see added to the record following appointments are:

Medical Appointment Information Record (MAIR)  
Psychiatric Appointment Information Record (PAIR)  
Dental Appointment Information Record (DAIR)

When an individual is dealing with a complex medical issue, it may be necessary for the Nurse to accompany the person to the appointment along with the support staff. Direct Support staff members may not be knowledgeable about a particular condition, diagnosis or treatment and may require the expertise of the Nurse to fully understand what the health care practitioner is asking them to do in terms of support. It may also be that there is some discrepancy in the care or treatment the person is receiving that may warrant the Nurse attending the appointment. Earlier in this Manual there was an explanation of “diagnostic overshadowing”. Remember, this is the tendency of health care practitioners to overlook symptoms caused by other conditions and attribute them instead to the person’s developmental disability. Many direct support staff members are not able to have these types of discussions with the practitioner and may require the assistance of the Nurse.

### **Hospital and Nursing Home Visits**

When someone you support is admitted to a hospital or nursing home, until and unless they are discharged from DDDS services, the nurse should visit within the first 48 hours or next working business day of admission and then at least weekly to stay informed about the person’s condition and any medications or treatments they are receiving. Daily phone contact by the nurse will also occur when the individual is in an acute care setting. “Diagnostic overshadowing” is a genuine threat to the health and well-being of people with developmental disabilities and extreme care should be taken to assure that significant symptoms are not attributed to the person’s disability instead of to a new or worsening health issue. Hospital and nursing home staff probably will not know the person very well and may not be familiar with intellectual or developmental disabilities in general. Your visit could mean the difference between something being taken into account or being dismissed. Visiting the person regularly while they are an in-patient will also assist you with discharge planning when the time arrives as well as providing reassurance and comfort to the person by the presence of a familiar person with whom they have an established relationship. It may also be beneficial in that the Nurse working with and for DDDS will understand how best to explain procedures and side effects to the person.



### Section 7 – -Policies, Protocols and Forms

Section Name	Date Read/Completed	Initials
ELP		
Team Meetings		
Emergency Team Meetings		
Transfer Planning		
Facility Discharge Meetings		
Attending Appointments as Appropriate		
Visits to the Home and Day Program		
Hospital and Nursing Home Visits		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## **Section 8 – The Electronic Record**

DDDS is currently contracted with Therap to maintain the electronic records of people receiving services. In order to access the records of an individual, you must be given electronic “permission” or access by an Administrator.

Some of the terms that will help users better understand Therap are:

### **Dashboard/FirstPage:**

This is the page that comes up after you log in. It contains all the Modules (i.e. T-Logs, GERs, and ISPs) that you are allowed to access and work on. It also notifies you of what you need to open/read/respond to since the last time you were logged in. You can switch between the Dashboard and FirstPage view. The Dashboard groups relevant modules in tabs making it easier for you to browse, while the FirstPage is a one page display of all the modules you have access to.

### **Individual Data Form (IDF):**

This document contains a comprehensive overview of the person including demographics, program history, allergies, contacts, insurance information, and other aspects necessary to assist a person such as required level of supervision, dietary guidelines, mobility guidelines etc.

### **Emergency Data Form (EDF):**

EDF is the portable version of the IDF that includes the most immediately necessary information for an emergency such as diagnoses, insurance information, and emergency contacts.

### **T-Log:**

T-Logs are a way to document things specific to the person receiving services. They can be used to record anything from daily activities, the monitoring of injuries, contacts, behavioral concerns, to general information. T-Logs replace Med Running Notes, Behavioral Notes, General Notes, Activity Logs, Recreational Logs, and Contacts with others (i.e., parents, siblings, cousins, and friends). This allows for extensive sharing of information with the neighborhood home/program Direct Support Professionals, Management, Specialists, Nurses, Area Director, Investigators, etc. The information in T-Logs will only be available to those who have been granted access to it. Information can be pulled up for Monitors and Licensing Inspectors as needed. A T-Log also allows all users to view when others have read it. T-logs should not be used to communicate between staff or team members, unless it is an issue that directly relates to the individual whose record the T-logs are attached to.

**General Event Reports (GER):**

GER is an incident report that can include injury, medication error, restraint, death, or the “other” category which may include things such as a person going to the emergency room, etc. Also included within GERs is the Witness Report used to gather further information about a given event from additional staff members who were present.

**Secure Communication (SComm):**

Thus is the intra-agency email system within Therap that all users can access to both send and receive messages in a secure, HIPAA compliant way. It can be used to e-mail anyone who is an active user in the system. You may also group people into User Groups for convenience in messaging as well as organizing folders system to store received messages. You can also view who has read any messages that you have sent.

**Behavior Event Record (BER):**

The BER is used to record data when tracking behavioral events including target behaviors, interventions, duration, intensity, and other relevant details. Note that staff will need to acknowledge a Behavior Plan before entering any data.

**Health Tracking (HT):**

Health Tracking keeps track of any data that refers to a person’s medical status including appointments, vital signs, height/weight, seizure activity, medication history, and intake/elimination, among others.

The Health Tracking application is a group of modules that record various aspects of an Individual's health status. Reports can be generated based on this data.

Administrators at the agency will need to assign appropriate “permissions” to grant users access to particular features of the Health Tracking application. Following is a list of available health tracking modules. The Nurse will use the ones that apply to the individual s/he is working with.

- Appointments Module
- Blood Glucose Module
- Height and Weight Module
- Immunization Module
- Infection Tracking Module
- Intake and Elimination Module
- Lab Test Result Module
- Medication History Module
- Menses Module
- Report Module

Respiratory Treatment Module  
Searching the Forms  
Seizures Module  
Skin and Wound Module

**Individual Medical Information:**

Individual Medical Information section contains Individual's Diagnosis record, Advance Directives which is used to document treatment preferences and designate a surrogate decision-maker and Allergy Profile to document an Individual's allergy information in detail.

## Section 8 – The Electronic Record

Section Name	Date Read/Completed	Initials
Dashboard		
Individual Data Form (IDF)		
Emergency Data Form (EDF)		
T-logs		
General Event Report (GER)		
SComm		
Behavioral Event Report (BER)		
Health Tracking		
Medication Assistance Record (MAR)		
Individual Medical Information		
Medicine data entry		

I, \_\_\_\_\_, have read and understood the  
(print name)

information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date

## Section 9 – DDS Commonly Used Acronyms and Abbreviations

ACRONYM/ ABBREVIATION	What It Means	What It Is/Does
AAIDD	American Association on Intellectual and Developmental Disability	AAIDD (formerly AAMR) is <i>the</i> professional association run by and for professionals who support people with intellectual and developmental disabilities.
AAR	Adult Abuse Registry	The Division of Long Term Care Residents Protection (DLTCRP) maintains a listing of all persons in the State of Delaware who have a substantiated case of abuse, neglect, mistreatment, and/or financial exploitation in their backgrounds
ACI	Arbitre Consulting, Inc.	Since July 2003 DDS has contracted with Arbitre Consulting, Inc. to administer and score all ICAP assessments in Delaware. ACI is a nationally recognized expert in the completion of the ICAP assessment instrument and administers the ICAP in several states.
ACT – SAT	American College Testing Assessment - Scholastic Aptitude Test	<p>The American College Testing Assessment (ACT) is designed to test your skill levels in English, math, reading, and science reasoning.</p> <p>The SAT Reasoning Test is a standardized test for college admissions in the United States. The SAT is administered by the College Board corporation, a non-profit organization in the United States, and is developed, published, and scored by the Educational Testing Service (ETS).</p>
ADA	American's with Disabilities Act	The Americans with Disabilities Act (ADA) ensures equal opportunity for persons with disabilities in employment, State and local government services, businesses that are

		public accommodations or commercial facilities, and in transportation. The ADA also mandates the establishment of telephone relay services for people who use TTYs (teletypewriters, also known as TDDs or telecommunications devices for deaf persons)
ADL	Activities of Daily Living	Activities of daily living (ADLs) are the things we normally do in daily living including any daily activity we perform for self-care (such as feeding ourselves, bathing, dressing, grooming), work, homemaking, and leisure
AMI	Asocial Maladaptive Index	An index located within the ICAP
APA	Authorized Provider Application	The application completed by a party or parties interested in contracting with the DDDS to provide services to the people it supports.
APS	Adult Protective Services  (Division of Services for Aging and Adults with Disabilities)	The Adult Protective Service (APS) Program responds to cases of suspected abuse, neglect, or exploitation of impaired adults. Specifically, the program serves persons who are aged 18 or over, who have a physical or mental impairment, and who are not living in a long term care facility (for example, a nursing home).
ARC	The ARC of Delaware	The Arc of Delaware is a non-profit organization of volunteers and staff working together to improve the quality of life for people with cognitive disabilities and their families.
ASD	Autism Society of Delaware	ASD was started in 1998 by a group of families who had common experience with autism. ASD is a group that reaches out to others facing autism, and they work together to improve opportunities for their children. ASD is an advocacy organization that works to connect the autism community together

		throughout Delaware. ASD is not associated with the national Autism Society
AT	Assistive Technology	Assistive technology includes assistive, adaptive, and rehabilitative devices and equipment. AT can promote greater independence for people with disabilities by enabling them to perform tasks that they were formerly unable to accomplish, by providing enhancements to or changed methods of interacting with the environment to accomplish such tasks.
BER	Behavioral Event Report	A Document contained in the Therap System used by team members to report on specific events as outlined in an Individual's Support Plan, or an required by emergency
BSP	Behavior Support Plan	An individualized plan of support written by a Behavior Analyst or a Psychological Assistant that instructs staff and others how to respond to certain behavioral issues.
CAR	Child Abuse Registry (also called the Child Protection Registry)	Maintained by the Department of Services for Children, Youth and their Families (DSCYF). A search of the Child Protection Registry will show if [a job or volunteer applicant] is a perpetrator in designated substantiated cases of child abuse or neglect.
CDS (UD CDS)	Center for Disabilities Studies at the University of Delaware	The mission of the Center for Disabilities Studies is to enhance the lives of individuals and families in Delaware through education, prevention, service, and research related to disabilities.
CLA	Community Living Arrangement	Living arrangements in the community – i.e., Neighborhood Group Home, Staffed Apartment, Supervised Apartment



CLASI	Community Legal Aid Society, Inc.	The Disabilities Law Program is a special project of CLASI and is designated by the Governor as the Protection and Advocacy agency in Delaware.
CLIMB	Consortium Leadership and Independence through Managing Benefits	This program serves to enhance the delivery of services to individuals with disabilities through benefits counseling by trained Benefits Specialists.
CM	Case Manager	An individual assigned to assist a person receiving services from DDDS to coordinate services and benefits
COR	Consumer (Client) Oriented Record	The written record, maintained by DDDS, which contains health and other information about each individual.
CP	Cerebral Palsy	Cerebral Palsy is a group of disorders associated with developmental brain injuries that occur during fetal development, birth, or shortly after birth. It is characterized by a disruption of motor skills, with symptoms such as spasticity, paralysis, or seizures.
DART	Delaware Authority for Regional Transit	An operating division of the Delaware Department of Transportation. Their mission is to design and provide public transportation services
DATI	Delaware Assistive Technology Initiative	The Delaware Assistive Technology Initiative (DATI) connects Delawareans with disabilities with tools they need to learn, work, and participate in community life safely and independently. DATI's services are available to all residents of Delaware. There are no eligibility limitations, other than Delaware residency.
DD	Developmental Disability	Developmental disability is a term used to describe life-long disabilities attributable to mental and/or physical or a combination of mental and physical impairments, manifested

		prior to age twenty-two.
DDDS	Division of Developmental Disabilities Services	The Division of the State of Delaware Department of Health and Social Services that provides services and support to individuals with developmental disabilities
DHSS	Delaware Health and Social Services	<p>DHSS is the largest cabinet department and the fifth largest employer in Delaware. DHSS employs 35% of all State employees. There are 12 divisions plus the Office of the Secretary within DHSS...</p> <ul style="list-style-type: none"> <li>- Office of the Secretary</li> <li>- Child Support Enforcement</li> <li>- Developmental Disabilities Services</li> <li>- Long Term Care Residents Protection</li> <li>- Management Services</li> <li>- Medicaid &amp; Medical Assistance</li> <li>- Public Health</li> <li>- Services for Aging &amp; Adults with Physical Disabilities</li> <li>- State Service Centers</li> <li>- Social Services</li> <li>- Substance Abuse and Mental Health</li> <li>- Visually Impaired</li> <li>- Office of the Chief Medical Examiner</li> </ul>
DLTCRP	Division of Long Term Care Residents Protection	<p>The Division of Long Term Care Residents Protection's mission is to protect residents in Delaware long term care facilities through:</p> <p>Promotion of quality of care, quality of life, safety and security, and</p> <p>Enforcement of compliance with State and Federal laws and regulations</p>
DMR	Division of Mental Retardation	The former name of the Division of Developmental Disabilities Services
DOE	Department of Education	The Department for the State of Delaware that provides services to individuals and their families in the educational system
DPH	Division of Public	DPH includes a wide range of programs and services aimed toward protecting and

	Health	improving the health of the people who live and work in Delaware
DSAAPD	Division of Services for Aging and Adults with Physical Disabilities	The mission of the Division of Services for Aging and Adults with Physical Disabilities is to improve or maintain the quality of life for Delawareans who are at least 18 years of age with physical disabilities or who are elderly.
DSCYF	Department of Services for Children, Youth and their Families	The Department of Services for Children, Youth and their Families' primary responsibility is to provide and manage a range of services for children who have experienced abandonment, abuse, adjudication, mental illness, neglect, or substance abuse. Its services include prevention, early intervention, assessment, treatment, permanency, and after care.
DSM – IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)	Psychiatric Diagnoses are categorized by the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition. Better known as the "DSM-IV," the manual is published by the American Psychiatric Association and covers all mental health disorders for both children and adults. It also lists known causes of these disorders, statistics in terms of gender, age at onset, and prognosis as well as some research concerning the optimal treatment approaches
DVR	Division of Vocational Rehabilitation	DVR's mission is to provide opportunities and resources to eligible individuals with disabilities, leading to success in employment and independent living
EDF	Emergency Data Form	A document contained in the Therap System that records for team use the Emergency Information necessary to support an individual. Includes pertinent health and insurance information and emergency contact information.

ELP	Essential Lifestyle Plan	A person centered plan, developed with the person receiving services, his/her family or guardian and other individuals providing support, that outlines in detail the individual's preferences, individual support needs, and lifestyle choices
EMI	Externalized Maladaptive Index	An index located within the ICAP
ETLA	Emergency Temporary Living Arrangement	A temporary residential placement for individuals receiving services with an approved provider while a permanent placement is being sought.
FICA	Federal Insurance Contribution Act	A U.S. law requiring a deduction from paychecks and income that goes toward the Social Security program and Medicare. Both employees and employers are responsible for sharing the FICA payments. FICA stipulates that there is a maximum that can be allocated to Social Security, while there is no maximum on what can go toward Medicare.
FSS	Family Support Specialist (Case Manager)	A case manager from the DDDS Family Support Unit.
GAC	Governor's Advisory Council (for Exceptional Citizens)	Provides leadership to improve the lives of exceptional citizens of Delaware of all ages through advice and advocacy.
GED	General Equivalency Diploma	A diploma earned instead of a High School Diploma. The recipient must pass a GED test
GER	General Event Report	A document contained in the Therap System that is used by team members to report events that are noteworthy or require follow-up. Replaces the DDDS Incident Report in Therap.
GMI	General Maladaptive Index	An index located within the ICAP

H.I.M.	Health Information Management	The unit in the DDDS that is responsible for overseeing the agency's archived records.
HCB OR HCBW OR HCBS	Home And Community Based Or Home And Community Based Waiver Or  Home And Community Based Services	The Developmental Disability Home and Community Based Waiver Program is administered by the DDDS. Services offered include all regularly covered Medicaid services (hospital, physician, lab, prescriptions) plus the following special waiver services:  Case Management  Day Habilitation  Institutional or In-home Respite Care  Residential Habilitation
HIPAA	Health Insurance Portability and Accountability Act	The HIPAA law is a multi-step approach that is geared to improve the health insurance system. One approach of the HIPAA regulations is to protect privacy. This is in Title IV which defines rules for protection of patient information. All healthcare providers, health organizations, and government health plans that use, store, maintain, or transmit patient health care information are required to comply with the privacy regulations of the HIPAA law
HOYO	Home of Your Own Program	Provides financing assistance for individuals with disabilities that are income eligible
ICAP	Inventory for Client and Agency Planning	An assessment tool used by DDDS to determine the support needs of individuals who are eligible for DDDS services, expressed as a number of hours of direct support needed per day for each individual.
ICF/MR	Intermediate Care Facility/Mental Retardation	Level of care based upon an evaluation that uses an Adaptive Behavior Scale.
ID (formerly IDF)	Individual Data Form	A document contained in the Therap System that records pertinent information about an

		individual, including name, address, date of birth, next of kin, etc.
IDT or ID Team	Inter-Disciplinary Team	The team of support professionals (usually composed of a Case Manager, Nurse, Behavior Analyst, Residential and Day Program staff) assigned to provide services to an individual.
IEP	Individualized Education Program	Each public school child who receives special education and related services must have an Individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly <i>individualized</i> document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability
IMI	Internalized Maladaptive Index	An index located within the ICAP
IOSA	Individual Outcome & Support Assessment	A document developed by DDDS as a tool to determine what's important to an individual and the current supports they receive. Required prior to writing the ELP.
IPE	Individual Plan for Employment	This plan is completed by the Division of Vocational Rehabilitation (DVR)
IPOPS	Individual Plan of Protective Oversight & Safeguards	A series of documents contained in the Therap System that records an individual's health & safety support needs. Types: General, Residential, Day Program, Work Center or Individualized Services. Many individuals will have more than one completed based on their current supports.
LD	Learning Disabled	Referring to an individual who has a learning

		disability
LDAF	Lower Delaware Autism Foundation	The Lower Delaware Autism Foundation (LDAF) was formed by a group of parents of children with autism. This group of parents decided to help make programs, services, and resources available to children and individuals with autism and their families, caregivers, and educators in Sussex County, Delaware.
LOC	Level of Care	A form completed as part of the Medicaid Waiver application
MANDT	The MANDT System of Behavior Support	A course of instruction that teaches people how to build relationships, have positive interactions, and respond in a crisis situation. The Division's current approved Behavior Support class for staff
MAP25	Comprehensive Medical Report	A form completed as part of the Medicaid Waiver application
MCI (Medicaid number)	Master Client Index	The unique identification number assigned to each individual receiving services from the State of Delaware Department of Health and Social Services
NCI	National Core Indicators	A collaboration among participating state agencies and Human Services Research Institute, with the goal of developing a systematic approach to performance and outcome measurement.
NH – 10	Review and Approval of Level of Care	A form completed as part of the Medicaid Waiver application
OAS	Office of Applicant Services	The Office of Applicant Services provides individuals and/or families with information about and assistance with applying for services from the DDDS
OBRA	Omnibus Budget Reconciliation Act	In 1987, President Ronald Reagan signed into law the first major revision of the federal standards for nursing home care since the

		1965 creation of both Medicare and Medicaid 42 U.S.C.1396r, 42 U.S.C. 1395i-3, 42 CFR 483. The landmark legislation changed forever society's legal expectations of nursing homes and their care. Long term care facilities wanting Medicare or Medicaid funding are to provide services so that each resident can "attain and maintain her highest practicable physical, mental, and psycho-social well-being."
OBRA	Federal Omnibus Reconciliation Act of 1987, also referred to as the Nursing Home Reform Act	A federally mandated program to determine whether persons with mental illness/mental retardation and/or a related condition are appropriate for admission to or continued residence in Medicaid certified nursing facilities and whether they require specialized services
OMB	Office of Management and Budget	The Office of Management and Budget was established July 1, 2005 by Governor Minner as part of her vision for the most efficient and effective operation of central state government services. This office supports State agencies to best utilize state assets, including people, land, facilities and financial resources.
OQI	Office of Quality Improvement (within the DDDS)	OQI staff duties include:  - Evaluate Provider compliance  - Complete Licensing Surveys  - Analyze and disseminate information  - Maintain information for the Division  - Promote improvement in supports
OT	Occupational Therapy	Occupational Therapy is the "use of productive or creative activity in the treatment or rehabilitation of physically, cognitively, or emotionally disabled people" (American



		Heritage Dictionary).
PARC	Policy and Records Committee	Committee of DDDS charged with the responsibility for updating and reviewing all DDDS policies and forms.
PCA	Personal Care Attendant	A person specifically employed or designated to help an individual with a disability with daily living needs.
PIC	Parent Information Center (of Delaware)	The Parent Information Center of Delaware, Inc, (PIC) is a statewide nonprofit organization and is Delaware's only federally mandated Parent Training and Information Center designated by the US Department of Education to provide support to families of children and youth with all disabilities from birth to age 26.
PLEP	Present Levels of Educational Performance	In conjunction with a student's IEP, the PLEP relates not only to a student's academic strengths and concerns, but skills, abilities and concerns related to his/her post-high school goals.
PM 46	Policy Memorandum #46	Policy Memorandum #46, Issued by the Department of Health and Social Services. This document defines "abuse, neglect and mistreatment", and instructs staff about the professional obligation to report.
PPD	Purified Protein Derivative  (the test used to detect Tuberculosis)	The tuberculosis skin test (also known as the tuberculin or PPD test) is a test used to determine if someone has developed an immune response to the bacterium that causes tuberculosis (TB).
PRC	Placement and Review Committee	The committee in DDDS whose responsibility it is to maintain a data base for individuals seeking residential services of available vacancies with approved residential service providers

PSR	Personal Spending Record	The document used to track the use of an individual's funds in a residential setting.
PT	Physical Therapy	Physical Therapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan.
QIDP	Qualified Intellectual Disabilities Professional	A Qualified Intellectual Disabilities Professional is someone who has specialized training in supporting people with developmental disabilities (mental retardation)
SSDI/OASDI	Social Security Disability Insurance / Old Age Survivors & Disability Insurance	Social Security Disability Insurance / Old Age Survivors & Disability Insurance pays benefits if you are "insured," meaning that you (or someone responsible for you) worked long enough and paid Social Security taxes.
SSI	Supplemental Security Income	Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people, who have little or no income; and it provides cash to meet basic needs for food, clothing and shelter.
ST	Speech Therapy	Speech Therapy addresses speech production, vocal production, swallowing difficulties and language needs.
TAPD	Training and Professional Development	The Office of Training and Professional Development (TAPD) is responsible for administration of the statewide training program for staff employed by or contracted with DDDS
THERAP	THERAP Services, LLC	THERAP Services is a web-based service organization that provides an integrated solution for documentation and communication needs of agencies providing support to people with disabilities, especially

		developmental disabilities.
T-Log	THERAP Log	A document contained in the Therap System that is used by team members to communicate with one another about every day events. Replaces “DDDS ID notes”.
UCP	United Cerebral Palsy	United Cerebral Palsy (UCP) is the leading source of information on cerebral palsy and is an advocate for the rights of persons with any disability. The UCP mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network.

### Section 9 – DDDS Commonly Used Acronyms and Abbreviations

Section Name	Date Read/Completed	Initials
DDDS Commonly Used Acronyms and Abbreviations		

I, \_\_\_\_\_, have read and understood the  
(print name)  
information provided in this section of the DDDS Nurse Consultant Resource Guide. I have had an opportunity to consult with my Supervisor and/or his/her designee and my questions have been answered.

\_\_\_\_\_  
Nurse's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Nurse Supervisor / Designee

\_\_\_\_\_  
Date